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Living with Bipolar Disorder: A Qualitative Investigation

Richard P. Freedberg
Western Michigan University

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LIVING WITH BIPOLAR DISORDER: A QUALITATIVE INVESTIGATION

by

Richard P. Freedberg

A Dissertation
Submitted to the
Faculty of The Graduate College
in partial fulfillment of the
requirements for the
Degree of Doctor of Philosophy
Interdisciplinary Health Sciences
College of Health and Human Services
Adviser: Nickola Nelson, Ph.D.

Western Michigan University
Kalamazoo, Michigan
August 2011
LIVING WITH BIPOLAR DISORDER: A QUALITATIVE INVESTIGATION

Richard P. Freedberg, Ph.D.
Western Michigan University, 2011

The specific aims of this study were to gain a broader understanding of the lived experience of adults with bipolar disorder and to explore how people diagnosed with bipolar disorder used cognitively, affectively, and spiritually oriented strategies to cope with life stressors and circumstances. The cognitive domain in this investigation was defined as those activities related to how one knows, thinks, or perceives phenomena in a way distinct from emotion. The affective domain referred to the feelings and emotions associated with phenomena that are distinct from cognitive reasoning or knowledge. The spiritual domain was defined as values, attitudes, and beliefs related to the sacred or holy that are distinct from cognitive and affective elements.

Eight English-speaking people age 18 or over who had been diagnosed with bipolar disorder for at least one year participated in hour-long, semi-structured interviews. The interviews were recorded and transcribed. A phenomenological method was used to analyze the transcripts. The four themes that emerged are: (a) diagnosis brings understanding accompanied by irrevocable change, (b) finding effective treatment is an interminable process, (c) bipolar disorder is the third partner in every relationship, and (d) caring for oneself is as important as receiving formal treatment.
Participants reported a wide variety of coping strategies. Cognitive means centered on self-monitoring of symptoms, managing the stigma of a bipolar diagnosis, and a conscious decision to care for oneself. The participants who were pregnant spoke of the challenges of living without their medications, constantly balancing their needs, and seeking information on bipolar disorder and pregnancy. Allowing oneself to feel hope for the future, joy in caring for a pet or in service to others, or satisfaction being alone or with others reflected affective means of coping. Participants frequently mentioned activities that had spiritual meanings for them, such as music, journaling, listening to nature, and formal practices such as prayer.

The findings from this study contribute to a broader understanding of living with bipolar disorder. They point to the importance of assessment and nurturance of client self-care strategies by mental health care providers.
You are invited to participate in a research project on *The Experience of Living with Bipolar Disorder*. Richard Freedberg is conducting this research. The results will help to fulfill dissertation requirements for the PhD in Interdisciplinary Health Sciences.

**What are we trying to find out in this study?**
This study is designed to broaden the understanding among nurses, physicians, and other health care providers of what it is like to live with bipolar disorder.

**Who can participate in this study?**
- Persons diagnosed with bipolar disorder for at least 1 year
- Must be 18 years or older
- Must speak fluent English
- Must be able to give clear focused answers to interview questions
- Must be willing to participate in an audio-taped interview lasting up to 2 hours and a second interview may be requested (participants are able to decline).

**Where will this study take place?**
A meeting room at the Lansing Community College Library or other mutually agreed location.

**What is the time commitment for participating in this study?**
The total time commitment is estimated as 1 to 2 hours plus any time involved in traveling to and from the interview site. A single interview is planned, but a second meeting may be requested if needed to clarify information from the first interview.

**What will you be asked to do if you choose to participate in this study?**
- Complete a short demographic questionnaire
- Give your permission for the interview to be audio recorded and for the interviewer to take some notes (Audio recordings and notes will be kept in a secure location and will be destroyed after the interviews have been transcribed and reports on the research have been completed.)
- Respond to questions asking for information such as age, employment status, race/ethnicity, and marital status.
- Respond to requests to describe experiences with and feelings about having bipolar disorder. (Participants are free to decline to answer any question or to decide to stop the interview at any time. The interviewer may decide to stop the interview if the participant seems to be experiencing distress.

**What are the risks of participating in this study and how will these risks be minimized?**
No harm is expected through participation in this study. Some people may feel sadness or anxiety while they describe their experiences with bipolar disorder. Participants may choose to stop the interview at anytime. If distressing feelings arise participants may contact their own medical provider for assistance or Ingham County
Community Mental Health Emergency Services at 517-372-8460 or the Listening Ear Crisis Center at 517-337-1717. Any participant or person who fails to qualify as a participant who does express current suicidal thoughts will be strongly encouraged to contact their provider or Ingham County Community Health Emergency Services. Richard Freedberg, the student investigator, can assist with those contacts. As a licensed mental health professional (Registered Nurse), Freedberg will stop the interview if he feels that is needed. As a mandated reporter, Freedberg is obligated to inform authorities if he feels a participant is at risk to him or herself.

What are the benefits of participating in this study?
There are no direct benefits to participants other than the satisfaction of sharing their story or contributing to the body of health care knowledge.

Are there any direct costs and is compensation associated with participating in this study?
There are no direct costs to participate. There may be indirect transportation and parking costs. Participants who complete the interview will receive a $25 gasoline card from a local service station in appreciation for their time and to help with any transportation and parking costs.

Who will have access to the information collected during this study?
The only people who will have access to the interview audio-recordings and notes are Richard Freedberg, the student investigator, and his advisor and dissertation committee members. The summarized information from all interviews and isolated quotes that cannot be identified with specific participants may be used in written reports or journal articles.

What if a person wants to stop participating in this study?
Participants can choose to stop at anytime for any reason without prejudice, penalty, or negative consequence if they decide to stop participating. The investigator, Richard Freedberg, also may decide to stop the interview if he judges it to be in anyone’s best interests.

Who should you contact if you have questions?
Any questions prior to or during the study can be directed to the doctoral student investigator, Richard Freedberg by calling 517-599-4169 or by emailing him at richard.p.freedberg@wmich.edu. Questions can be directed to his faculty advisor, Dr. Mary Lagerwey by calling 269-387-8167 or emailing mary.lagerwey@wmich.edu. Participants also may contact the Chair of the Human Subjects Institutional Review Board at 269-387-8293 or the Vice President for Research at 269-387-8298 if questions arise during the course of the study. This consent document has been approved for use for one year by the Human Subjects Institutional Review Board (HSIRB) as indicated by the stamped date and signature of the board chair in the upper right corner. Do not participate if the stamped date is more than one year old.

I have read this informed consent document. The risks and benefits have been explained to me. I agree to take part in this study.

Please Print Your Name

Participant’s signature
Date: June 25, 2010

To: Nickola Nelson, Principal Investigator
   Richard Freedberg, Student Investigator for dissertation

From: Amy Naugle, Ph.D., Chair

Re: HSIRB Project Number: 10-04-08

This letter will serve as confirmation that your research project titled “Living with Bipolar Disorder” has been approved under the full category of review by the Human Subjects Institutional Review Board. The conditions and duration of this approval are specified in the Policies of Western Michigan University. You may now begin to implement the research as described in the application.

Please note that you may only conduct this research exactly in the form it was approved. You must seek specific board approval for any changes in this project. You must also seek reapproval if the project extends beyond the termination date noted below. In addition if there are any unanticipated adverse reactions or unanticipated events associated with the conduct of this research, you should immediately suspend the project and contact the Chair of the HSIRB for consultation.

The Board wishes you success in the pursuit of your research goals.

Approval Termination: April 21, 2011
ACKNOWLEDGEMENTS

The journey toward completion of this dissertation has been a fruitful and gratifying one. I met some fascinating people and was cognitively, affectively, and spiritually (to use my theoretical framework) challenged during my coursework and research. Exceedingly helpful people guided and encouraged me throughout this endeavor and I would like to thank them.

Dr. Nickola Nelson, my academic advisor and a dissertation committee member, inspired me by her stunning attention to detail, willingness to lead by example, and her unyielding expectation of commensurate effort from her students. Any skill in academic writing that I may possess, I owe to her.

Dr. Mary Lagerwey, the chair of my dissertation committee, guided me along the often tortuous path of examining the world from a qualitative research perspective. My inclination and appreciation for this vantage point grew under her tutelage. Dr. Lagerwey invariably modeled academic rigor and a genuine abiding regard for all the participants who share their stories with us in every investigation.

Dr. Kieran Fogarty taught me statistics (much of which I surprisingly almost remember) and served on my dissertation committee. His pragmatic feet-firmly-planted-on-the-earth stance grounded me and gave stability to my sometimes impulsive tangential thinking.
Acknowledgments—Continued

Thank you Dr. Victoria Ross, a committee member, for your priceless wisdom and advice. I will ever recall your admonitions to “always keep the chair of your committee happy” and “never forget to give your reader a roadmap.”

May God keep all of you in His care and richly bless you!

Richard P. Freedberg
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CHAPTER 1

INTRODUCTION

Overview

The aims of this investigation were to add to the understanding of the experience of living with bipolar disorder. Chapter One introduces the area of interest and defines constructs used throughout this research; Chapter Two demonstrates the lived experience of bipolar disorder is an under researched phenomenon; Chapter Three describes the qualitative methods used to explore this topic with individuals diagnosed with the disorder; Chapter Four presents the results; and Chapter Five discusses the results with reference to prior research and implications for future research. It is hoped the findings from this study will serve to guide nurses and other health care providers in their therapeutic relationships with people with bipolar disorder.

I am a nurse who approached the study from a nursing perspective. Nurses focus attention, in part, on the human response to any disorder with which people may be diagnosed. Nursing assessment examines the impact of a disorder on one’s emotional or affective status, cognition, and spirituality. The American Nurses Association (ANA) Standard 1—Assessment (2010) states:

The registered nurse collects comprehensive data including but not limited to physical, functional, psychosocial, emotional, cognitive, sexual, cultural, age-related, environmental, spiritual/transpersonal, and economic
assessments in a systematic and ongoing process while honoring the
uniqueness of the person. (p. 32)

I am also a student in interdisciplinary health sciences who sought to augment my
nursing perspective through inclusion of knowledge and conceptual frameworks from
other disciplines. This study sought to appreciate the impact of living with bipolar
disorder on aspects of participants’ lives from cognitive, affective, and spiritual
perspectives.

The remainder of this introduction lays the foundation for this investigation. A
background section clarifies bipolar disorder as a collection of three different conditions
and explains their place in the context of persistent and severe mental health disorders.
Defining characteristics and lifetime prevalence of each condition is then considered. A
brief introductory discussion of living with mental illness follows and then the study
purpose is explained. This introduction ends with a discussion of the methodological
approach and the research question that guided the investigation.

Definitions of Constructs

Mental Health Disorder

Bipolar conditions, the area of interest in this research, are persistent and often
severe mental health disorders. The standard reference used by mental health providers
to diagnose mental health conditions is the Diagnostic and Statistical Manual of Mental
Disorders (DSM-IV-TR) published by the American Psychiatric Association (2000). The
DSM-IV-TR defines mental disorder as “a clinically significant behavioral or
psychological syndrome or pattern that occurs in an individual and that is associated with present distress or disability or with a significantly increased risk of suffering, death, pain, disability, or an important loss of freedom” (APA, 2000, p. xxx). This definition takes into account cognitive and affective or emotional distress and maladaptation to daily stressors, in addition to objectively measured behaviors and alterations in sensory perception. Although exploration of all high-prevalence mental health conditions is beyond the scope of this investigation, a detailed examination of the lived experience of bipolar conditions within the framework of cognitive, affective, and spiritual domains can contribute to the understanding of an important and understudied segment of the population of people with chronic mental disease.

Bipolar Disorder

Bipolar disorder is experienced in three forms: bipolar 1, bipolar 2, and cyclothymic disorders. The DSM-IV-TR (APA, 2000) is the standard diagnostic source in the United States and is used here to provide defining characteristics of these conditions. People with each of the three bipolar disorder forms can exhibit alternating cycles of depressed and elevated periods of mood and energy, but the range and intensity between these two poles vary with the condition type.

The lifetime prevalence of bipolar 1, 2, and cyclothymia in United States community samples respectively are 0.4-1.6%, 0.5%, and 0.4% to 1% according to the American Psychiatric Association (APA, 2000). The most recent Annual Review of Public Health (Kessler & Wang, 2008) states the lifetime prevalence for the collected bipolar disorders is 3.9% and the National Institute of Mental Health (NIMH, 2008)
estimates 5.7 million American adults age 18 and over have one of the three forms of bipolar disorder in any given year.

It was anticipated that potential participants in this study would know they had been diagnosed with bipolar disorder but might not actually be aware of the exact clinical type. Consequently, I expected that participants might include people who had been diagnosed with any of the three forms. Therefore, this study uses the label “bipolar disorder” as a generic term comprising any of the three types,

Bipolar 1 Disorder

The essential defining characteristic of bipolar 1 disorder is a clinical course that includes one or more manic episodes (APA, 2000). A manic episode is identified by a discrete period lasting at least one week in which there is an abnormal and persistent elevated, expansive, or irritable mood. There may be: (a) euphoria, (b) racing thoughts, (c) an increase in goal directed activity, (d) grandiosity, (e) inflated self-esteem, (f) delusions, or (g) hallucinations. Almost invariably, there is a decreased need for sleep.

Bipolar 2 Disorder

The critical feature of bipolar 2 disorder is a clinical course of one or more major depressive episodes accompanied by at least one hypomanic episode (APA, 2000). Hallucinations and delusions are not present in hypomania. A hypomanic episode is identified by an abnormal and persistently elevated, expansive, or irritable mood that lasts at least four days. This is accompanied by at least three other symptoms such as (a) decreased need for sleep, (b) inflated self-esteem or grandiosity (nondelusional), (c) flight
of ideas, distractibility, (d) increase in goal-directed activities, (e) pressured speech, and (f) excessive involvement in pleasurable activities.

Cyclothymia Disorder

The defining characteristic of cyclothymia, a milder form of the bipolar experience, is a chronic, fluctuating mood disturbance involving numerous periods of hypomania and depression (APA, 2000). People with cyclothymia experience episodes of hypomania alternating with mild depression for at least two years. It is important to note that the symptoms experienced by people with cyclothymia fail to meet the severity thresholds of bipolar 1 and 2.

Cognitive Domain

The cognitive domain is one area that may be most familiar to many people. “I think” is a phrase many people use often, and one that falls into the cognitive domain. For the purposes of this investigation, the cognitive domain is defined as those activities related to how one knows, thinks, or perceives phenomena in a way distinct from emotion. Cognitive distress can occur when reasoning or thinking efforts fail to lead to successfully adaptive responses to challenging life circumstances.

Affective Domain

The affective domain is a second area that is familiar to most people. People often initiate declarations with “I feel.” In this study, the affective domain refers to the feelings and emotions associated with phenomena that are distinct from cognitive
reasoning or knowledge. Affective distress can be feelings of despair, powerlessness, or hopelessness.

Spiritual Domain

The spiritual domain in this study is defined values, attitudes, and beliefs related to the sacred or holy that are distinct from cognitive and affective elements. Many people, including lay, ordained, or religious congregation members associated with formal religions, engage daily in spiritual practices. However, the spiritual domain may not be as much a part of the conscious world for some people as the cognitive and affective domains. In addition to cognitive and affective distress, nursing values the assessment of one’s spirituality and, indeed, has a diagnosis label of “Spiritual Distress.” “Spiritual Distress” is the “state in which an individual or group experiences, or is at risk of experiencing, a disturbance in the belief or value system that provides strength, hope, and meaning to life (Carpenito-Moyet, 2006, p. 468).”

This investigation also considered the role, if any, of spirituality. Spirituality in various manifestations from formal religious practice to less structured belief systems also shows up in the literature as an important coping technique used to find meaning. For example, Black (1998) interviewed three elderly women who had lost an adult child to a violent death. Analysis revealed atypical religious views in which religious practices are a present comfort, but belief in an afterlife maybe lacking. Also, McNulty, Livneh and Wilson (2004) surveyed 50 people diagnosed with multiple sclerosis and found spiritual well-being exerted measurable influence on adaptation to chronic disease and mitigated the effect of uncertainty. Wilding, May, and Muir-Cochrane (2005) conducted
interviews to gain a greater understanding of spirituality in the lives of people living with chronic mental illness and concluded that mental health providers need to include assessment of spiritual beliefs and practices as sources of coping and support in their clients.

Living with Mental Illness

The lives of people living with severe and chronic mental health disorders such as bipolar disorder can be viewed as lying along a continuum of functional ability in multiple domains including cognition, affective experience, and spirituality. To be succinct, the intensity of symptoms and distress experienced by people with an identical diagnosis varies. The continuum ranges from episodes of severe functional loss and distress at one end, through successful adaptation in daily living in the center, to remarkable accomplishment at the other end. Negative impacts on people with chronic mental illness are documented and include periodic turmoil and distress (Cole, 2004), intermittent chaos (Jamison, 1995), and often frank psychotic episodes (Driscoll, 2004). However, questions linger. Some people with bipolar disorder live full, rich, productive lives and yet others struggle. It seems the full breadth of the lived experience of people with bipolar disorder has yet to be fully explored and described.

The literature describing living with bipolar disorder is limited. Researchers have undertaken several investigations that examined selected facets of the lives of people diagnosed with bipolar disorder. For example, Laxman, Lovibond, and Hassan (2008) conducted a systematic literature review examining the impact of having bipolar disease on employment. Their analysis indicated that symptoms related to bipolar
disorder can create significant negative effects on work relationships, attendance, and function, which lead to substantial costs for employers. In a quantitative investigation, Anderson-Darling, Olmstead, Lund and Fairclough (2008) studied adherence to medication regimens and they found that people diagnosed with bipolar disorder who were adherent with their medications experienced fewer symptoms and possessed a stronger belief that their own behaviors controlled their health status.

Investigations using qualitative methodologies specifically to study the broader total lived experience of bipolar disorder as opposed to particular aspects are rare. In her doctoral research, Driscoll (2004) conducted audio recorded interviews with eleven women diagnosed with bipolar disorder and analyzed the transcripts with a phenomenological method. Four themes emerged from analysis of interview data: a) melancholy to mayhem at the flick of a switch, b) dwelling in the maze, the journey toward diagnosis and treatment, c) emerging in steadiness: regaining control, and d) cultivation of a new self.

Healthcare providers and lay people have described their personal experiences with bipolar disorder in a variety of forms. For example, Jamison (1995), a clinical psychologist, penned an account of her life with bipolar disorder aimed at both healthcare professionals and interested lay readers. Burnard (2007) employed her experience as a nursing researcher and used an autoethnographic methodology to recount her lived experience as a provider who is also a consumer needing treatment for long-standing bipolar disorder.

Overall, the lived experience bipolar literature is sparse and additional research is needed to add to the understanding of living with this condition. A broadened
understanding is important because it may aid healthcare providers in delivering more effective and patient-centered interventions.

**Purpose of the Study**

In an effort to reach a fuller understanding of all dimensions of living with bipolar disorder, I used a cognitive (thinking) – affective (feeling) – spiritual (formal or informal beliefs and practices) framework underpinned by Standard 1 – assessment (ANA, 2010). The specific aims of this study were to gain broader understanding of the lived experience of adults with bipolar disorder and to consider the impact, if any, on cognitive, affective, and spiritual domains. In addition, I wanted to know how people diagnosed with bipolar disorder used cognitively, affectively, and or spiritually oriented strategies to cope with life stressors and circumstances.

**Investigation Approach and Research Question**

I was interested in the thoughts, feelings, significant events, challenges, accomplishments, familial, and friend relationships. These are components that build a life, in this case as experienced by people who have been diagnosed with bipolar disorder. A phenomenological approach is well suited to investigations of lived experience (Graneheim & Jansson, 2006; Kowlessar & Corbett, 2009; Patton, 2002). In general, such an approach seeks to find the essential meaning or essence of a particular phenomenon for a person or group of people (Patton, 2002). Specifically, this investigation attempted to understand how people with a bipolar condition experienced the joys and sorrows, frustrations and accomplishments, and the successes and challenges
in day-to-day existence by addressing the question: “What is the lived experience of a person diagnosed with bipolar disorder?”
CHAPTER 2

REVIEW OF THE LITERATURE

Overview

Chapter Two describes the literature review that grounded this investigation. It begins by presenting the search strategies I used to identify literature on bipolar disorder, “lived experience,” and phenomena associated with chronic illness. Results of each of these searches are then discussed under the headings: Research on Lived Experience, Lived Experience of Caregivers of People with Chronic Mental Illness, Lived Experience of People with Mental Illness, Lived Experience of Bipolar Disorder, and Phenomena Commonly Associated with Chronic Disease. The summary shows that this review demonstrates a gap in the literature related to living with bipolar disorder and illustrates the significance of this investigation.

Search Strategies

Bipolar Disorder

A comprehensive literature search was undertaken using MEDLINE, CINAHL, SCOPUS, OVID, PsychInfo, First Search, and Google Scholar search engines. The goal was to identify and critique the results of prior investigations and discover potential gaps in the literature. The initial key words were “bipolar,” “bipolar disease,” and “bipolar disorder.” Forty thousand plus sources emerged. This number dropped to approximately 7,000 when the search was limited to peer-reviewed articles published in the last five
years. Most of these studies described bipolar disorder assessment, pharmacological management, role of neurotransmitters and other anatomical and physiological considerations and implications.

Bipolar Lived Experience

The area of interest in this study is exploring what it is like to live with bipolar disorder. This led the search in a different direction. The approach of studying one’s “lived experience” with a particular condition or circumstance is well known in qualitative research. An initial search of the “lived experience” literature elicited more than 2000 peer-reviewed articles. When I refined my initial literature search of bipolar disorder by excluding all but “lived experience” articles, fewer than 15 sources initially emerged. All of these but two examined the lived experience of caregivers of people with bipolar disorder. Only two investigations interviewed people with bipolar. I therefore broadened this search to include book- and article-length autobiographical accounts. I found eight either autobiographical or biographical accounts that I will describe in detail in a later section.

Phenomena Potentially Associated with Bipolar Disorder Search Strategy

Prior to the current search, I prepared an annotated review of the literature describing the diagnosis, treatment, and lived experience of mental health disorders in the United States. That review highlighted descriptions of three phenomena that are sometimes experienced by people caring for or people with chronic medical conditions and severe and persistent mental health disorders. These phenomena are chronic sorrow,
self-transcendence, and uncertainty. In the current search, I found no link in the literature between these four phenomena and persons with bipolar disorder. However, the extant literature describing the lived experience of bipolar disorder is scant. I wondered whether any of these three phenomena would emerge in the present investigation.

Research on Lived Experience

A thorough review of the literature showed that the lived experience phenomenon has been widely investigated by health care providers from several disciplines using assorted methods in a variety of populations under varying circumstances. A single search of the SCOPUS database using the search term “lived experience,” for example, returned 2,267 nursing, medicine, and psychology articles detailing qualitative, quantitative, and mixed methods investigations from 1990 to the present about a variety of conditions. The preponderance of these articles considered living with a disorder from a caregiver’s perspective.

The Caregiver Experience

Much of the lived experience research, moreover, describes the experiences of caregivers for loved ones with medical disorders rather than mental illness. Kearney and Griffin (2001), for example, used a phenomenological approach to explore the experiences of parents of four children who had developmental disabilities. Six parents, including two couples and two single mothers, participated in a series of interviews. Their children had a variety of disabilities. One four-year-old boy had brain damage acquired at age two from a near-drowning episode; a second four-year-old boy had brain
damage due to meningitis at seven months; a third child, a six-year-old girl, had cognitive impairments attributed to an intrauterine viral infection; and the fourth child, a three-year-old boy, had Down’s syndrome. In this phenomenological investigation, the six parents were interviewed over a period of 18 months. One question that was asked at each initial interview was, “Can you tell me about your experiences of living with (name of child)?” (p. 584). The investigators found that parents reported disappointment, sorrow, and other negative emotions; however, parents of these children also reported feeling joy at times and spoke of hope, strength, and love. The phenomenological approach captured data that might not have been collected through a questionnaire.

Hayes (2001) also used a phenomenological method to conduct semi-structured interviews with five adult participants who were living with Type 1 diabetes. Four themes emerged: fear of the future, negative attitudes of others, regrets and difficulties managing the condition.

Some research explored living with various chronic conditions, including bipolar disorder. Lundman and Jansson (2007) interviewed eight people between the ages of 55 and 79 who had been diagnosed with a chronic medical disease. The eight people had the following diagnoses: rheumatoid arthritis, Bechterew’s syndrome (now known as ankylosing spondylitis), polio, stroke, fibromyalgia, and bipolar disorder. The aim of the study was to describe the meaning of living with a chronic disease. Five themes emerged: (1) loss and uncertainty threaten everyday order, (2) learning one’s coping capacity and living accordingly, (3) maintaining fellowship and belonging, (4) having a source of strength, and (5) building anew. The findings contributed to the understanding of how
people live with chronic illness. Lundman and Jansson appeared to presume that all chronic illnesses would produce similar experiences.

Lived Experience of Caregivers of People with Chronic Mental Illness

Another area of research focuses specifically on caring for people diagnosed with mental illness. Doornbos (1997), for example, sought to identify the common problems encountered by caregivers of young adult family members with chronic severe mental illness through administering a questionnaire to 108 caregivers. Participants were asked to answer two questions. The first asked: “What are the greatest problems that you encounter as a result of having a mentally ill family member?” (p. 23). The second asked: “What are the best ways that you have found to cope with these problems?” (p. 23). Caregivers provided written responses to these open-ended questions. Doornbos identified an array of problems including lack of freedom, burden, coping with symptoms and behaviors, negative stigma, unending grief and fear for the future. However, these findings may not reflect the full experience of mental health disorders. They also present only perspectives of caregivers; that is the problems caregivers encounter and the coping strategies they employ. They do not explore the lived experience of the person with the disorder.

Continuing with the caregiver focus, Tuck, du Mont, Evans and Shupe (1997) used a phenomenological methodology to study the experiences of nine parents, each of whom was caring for an adult child with schizophrenia. These parents described the experience as destructive and filled with loss. Seven themes emerged. Parents were struggling to reframe events as normal, seeking help, dealing with the transformation of
their loved child, living with changing levels of hope, engaging in endless caring, gathering meaning, and preserving self. These parents viewed life as being full of demands and struggles to survive.

Caregivers of loved ones with mental disorders have reported feeling other emotions as well. Howard (1998) interviewed fathers of adult children with schizophrenia. Her participants indicated that they felt guilt thinking they contributed to the disorder through genetic inheritance and that they fear for the future of their child. Similar findings emerged in Mohr’s (2001) study of parents of mentally ill children but these participants also described unspecified fears, anguish, and living with a nightmare.

Not all caregiver emotions are negative. Tweedell, Forchuk, Jewell, and Steinnagel (2004) used a naturalistic inquiry design with nine families to understand their subjective experiences related to a relative’s recovery or non-recovery from psychosis. The researchers reported an unexpected finding. Eight of nine families interviewed reported positive outcomes including improved interpersonal relationships between family members providing care and between caregivers and care recipients.

Few studies have explored the experience of caring for people diagnosed with bipolar disorder. In one of the few examples, Jönsson, Skärsäter, Wijk, and Danielson (2011) used a hermeneutic phenomenology method to interview 17 family members of people with bipolar disorder. The investigators concluded family members felt alone with their experiences, and they struggled to make sense of them while attempting to maintain normality in daily life.

The above discussion illustrates the preponderance of lived experience literature describes that lived experience from a caregiver perspective. Even though a few of these
studies included participants diagnosed with bipolar disorder, the aim of current investigation was to gain an understanding of a personal experience of living with the disorder. Understanding the caregiver experience is not the primary consideration of the current investigation but it may contribute to putting the lived bipolar experience into context. I further narrowed my literature review to investigations from the vantage point of a person diagnosed with mental illness.

Lived Experience of People with Mental Illness

Although much of the lived experience literature related to mental illness describes the lived experience of caregivers, some research was found that considered a particular mental illness from the perspective of the person diagnosed with it. Most of these studies, however, did not directly or exclusively address bipolar disorder.

Chafetz (1996), for example, conducted life-history interviews of 43 people with chronic severe mental illness. Participants were recruited from outpatient clinics, treatment programs, and skilled nursing facilities. Their diagnoses were with schizophrenic illnesses, bipolar disorder, or recurrent depression. The participants described individual learning and personal choices that influenced the course of mental illness over time.

Hayne and Yonge (1997) used a hermeneutical approach to analyze the published written narratives of 40 people living chronic mental illness. One dominant theme centered on the turmoil between self and one’s mind; another theme was that receiving a mental health diagnosis was akin to hearing a death sentence. Mourning for lost dreams for the future also emerged as a theme.
Fredriksson and Lindström (2002) used a method they term hermeneutic phenomenology to interpret the 20 “caring conversations” between eight patients with mental health disorders and three psychiatric nurses over a period of two years. The findings indicated these hospitalized psychiatric patients first concealed suffering, but if allowed to narrate freely, they were able to confront suffering and shame in a way that opened up the potential for sustaining relationships with others.

Diaz-Caneja and Johnson (2004) conducted semi-structured interviews of women with schizophrenia, bipolar affective disorder, or severe depression with psychotic symptoms. Participants in this study reported feeling unable to openly discuss their problems due to experiences of being shunned or isolated by family and friends. The mothers among the participants reported that their children also encountered the effects of stigma associated with mental illness. Mothers of neighborhood children, for example, often viewed the children of the participants as undesirable playmates for their own children. Despite experiencing stigmatization and the periodic negative impact of parenting on their own mental illness, participants described motherhood as rewarding and sustaining.

Thompson, Hunter, Murray, Ninci, Rolfs, and Pallikkathayil (2008) conducted a photo-voice study of seven adult people living with various forms of chronic mental illness. Participants were asked to photograph objects that symbolized their lives with mental illness and then write a narrative explaining the photo. Participants selected a variety of objects. For example, one person photographed a collage of items that had been used to physically abuse her; another participant took a picture of the computer he had used to connect with others. Four major themes emerged in this investigation: (a)
feeling misunderstood and invisible in the world; (b) attempting to gain control and be safe through various actions and activities; (c) making an ongoing effort to repair injured self-esteem; and (d) using various coping skills. Participants reported they enjoyed the process and believed they were able to capture meaningful images that effectively communicated their experience of living with a mental illness.

Nehls (1999) interviewed 30 adult females with borderline personality disorder. The women reported three chief areas of concern: living with a label, living with self-destructive behavior perceived as manipulation, and living with limited access to care. Nehls and Sallmann (2005) interviewed 30 adult women with a history of physical and/or sexual abuse paired with substance abuse and mental illness. The abused women perceived themselves as living fearfully in a restricted world. However, participants stated that these feelings were helped by having their stories heard.

Several studies explored living with particular disorders rather than mental illness in general. For example, Olson, Vera, and Perez (2007) examined the lived experience of obsessive-compulsive disorder (OCD). The investigators conducted audio-taped, in-depth interviews with ten people diagnosed with OCD. The participants reported that they were most concerned with care and treatment, developing the skills to cope and maintain independence, and feelings connected to people perceived as a source of strength. Stigsdotter-Nyström and Nyström (2007) interviewed 10 people about living with recurrent depression. Unipolar depression, bipolar 1 disorder, and bipolar 2 disorder were listed in the inclusion criteria. Participants reported feeling alienated from themselves and other people.
Lived Experience of Bipolar Disorder

Much of the bipolar literature discusses the impact of bipolar disease on specific domains within one’s life. These include: employment (Laxman, Lovibond, & Hassan, 2008), adherence to medication (Anderson-Darling, Olmstead, Lund & Fairclough, 2008; Hassan & Lage, 2009), stigma (Sajatovic e al., 2008), coping (Goossens, Knoppert-van der Klein, & Achterberg, 2008; Russell & Browne, 2005) and self-development (Inder, Crowe, Moor, Luty, Carter, & Joyce, 2008).

Although research explored living with other mental health disorders, I found only two studies that described the experience of people living with bipolar disorder from their perspectives. As previously discussed, Driscoll (2004) conducted audio recorded interviews with 11 women diagnosed with bipolar disorder and analyzed the transcripts with a phenomenological method. Four themes emerged from analysis of interview data: a) melancholy to mayhem at the flick of a switch, b) dwelling in the maze, the journey toward diagnosis and treatment, c) emerging in steadiness: regaining control, and d) cultivation of a new self. Jönsson, Wijk, Skärsäter and Danielson (2008) sought to describe the views of 18 participants diagnosed with bipolar by interviewing them about their illnesses and their futures. These researchers found daily life for their participants was insecure and challenging. The participants also indicated having hope to influence the bipolar condition made it easier to manage their day-to-day functioning.

The paucity of bipolar lived experience research led me to consider non-research sources about the experience of living with bipolar disorder. Jamison (1995), a clinical psychologist and researcher who is recognized as an authority in the treatment of bipolar disorder, wrote a book about her life with bipolar disorder that is aimed at both healthcare
professionals and interested lay readers. There are a few other article-length autobiographical accounts. Lundin (1998) described his 20-year experience with bipolar disorder and how he views himself as an advocate to help people with this condition overcome the self-deprecation, depression, and denial associated with stigma. Cole (2004) spoke of his bipolar journey that began when he was the shadow Attorney-General in the State Parliament in Victoria Australia. Behrman (2005) described 10 years of his experience in a short essay. He related the feelings associated with being misdiagnosed by eight of his providers as having depression alone, his multiple treatment regimens, finding success as a public relations person and art dealer, and undergoing a brief prison sentence for counterfeiting. Singleton (2006) reported a case study of an adolescent who was severely ill with bipolar disorder. Burnard (2007), a nursing researcher, wrote an autoethnographic account of herself, both as a provider and as a patient needing to receive treatment for her long-standing bipolar disorder.

Sanders (2008) described the 26 years since her diagnosis with bipolar disorder. She recounted the long series of medications with which physicians tried to control her manic symptoms. Several of the medications triggered life-threatening adverse reactions. Sanders also wrote about the strained relationships she had with some providers and how those conflicts limited the effectiveness of treatment.

Kwok (2009) described her experience as a Chinese woman with bipolar disorder living in Canada. She was diagnosed with bipolar disorder shortly after she emigrated from Hong Kong. After diagnosis, she reported feeling lonely, abandoned, and isolated. She described her experience with medication adverse effects including one episode of coma and her journey to regain a productive life teaching English as a second language to
new immigrants. An occupational therapist (Hatchard & Missiuna, 2009) described her
diagnosis during college, inpatient psychiatric hospitalizations, and her subsequent
adjustment to her disease.

Phenomena Commonly Associated with Chronic Disease

In my review of the literature that describes living with a chronic disease, I found
that specific phenomena, including chronic sorrow, uncertainty, and self-transcendence,
often were part of that lived experience. Although prior literature did not establish any
link between these phenomena and living with bipolar disorder, I wondered whether
characteristics of these phenomena would emerge in this investigation. Therefore, the
literature was summarized addressing these phenomena.

Chronic Sorrow

Grief was initially thought to be a linear process involving a precipitating loss,
denial, grief, focusing outward, a process of adjusting to the loss and finally acceptance
and closure. This linear process, however, does not correspond with actual observations.
Olshansky (1962, 1966) was an early observer who described a proposed phenomenon
that he termed “chronic sorrow.” He suggested that “most parents who have a mentally
retarded child suffer from a pervasive psychological reaction, chronic sorrow, which has
not always been recognized by the professional personnel—physicians, psychologists,
and social workers—who attempt to help them…” (1962, p. 190). Olshansky (1962,
1966) asserted further that, although parents do indeed come to “accept” having a
defective child they continue to experience intermittent sadness as long as the child or
parent lives. The sadness arises from milestones that are never achieved. Moreover, Olshansky (1962) claimed that this is a normal psychological reaction and not pathological.

Subsequent authors have further explored the concept of chronic sorrow and the growth of professional health care providers’ understanding of chronic sorrow. Wikler, Wasow and Hatfield (1981) surveyed 100 parents of cognitively impaired children and 100 social workers involved with families with disabled children in an effort to investigate chronic sorrow understanding and attitudes. Parents and social workers readily agree parents experience intermittent crises and sorrow throughout the child’s development, but social workers tended to underestimate the impact on parents. These findings ran counter to the then-prevailing professional view that sorrow could be overcome at some point of acceptance.

Analysis of the extant literature on chronic sorrow attempted to broaden the understanding of this phenomenon. Freeman-Copley and Bodensteiner (1987) and Clubb (1991) each summarized the extant literature in early practice articles designed to articulate the concept of chronic sorrow to care providers and to offer multidisciplinary clinical practice guidelines. Fraley (1990) summarized her research of parental chronic sorrow responses to the stresses related to caring for a disabled child. In addition to the feelings of recurrent grief, helplessness, frustration, and anger found in other studies, Fraley also reported participants experienced self-blame for an early birth. Teel (1991) analyzed the literature to distinguish chronic sorrow as different from bereavement, grief and morning. Lindgren (1992) systematically reviewed the extant chronic sorrow literature. Through her analysis, she identified four clinical attributes: (1) perception of
sorrow or sadness over time appears not to have a predictable end, (2) sadness is cyclical and recurrent, (3) internal or external triggers bring to the person’s losses to mind, and (4) sadness is progressive and can intensify in the years following the initial loss.

A collection of nurses established a group, the Nursing Consortium for Research on Chronic Sorrow, to define a research and intervention approach for nurses. Burke, Hainsworth, Eakes, and Lindgren (1992) introduced and Eakes, Burke, and Hainsworth (1998) subsequently refined a middle-range nursing theory of chronic sorrow that was developed using concept analysis, a critical review of research, and the validation from qualitative research. The qualitative studies had a common purpose to pilot a specific instrument, the Burke/NCRCS Chronic Sorrow Questionnaire with people experiencing various loss situations and chronic illnesses. The instrument became part of the model for the interview guide in the current investigation (see Chapter Three).

As the prior review indicated, many investigations over the years have examined the lived experience of the suffering and distress of people diagnosed with or providing care to loved ones with chronic physical or mental illness. Hainsworth (1994) used a chronic sorrow instrument and semi-structured interviews to explore the lived experience 10 participants with multiple sclerosis. She found that 80% demonstrated the presence of chronic sorrow, an intermittent chronic experience of loss and sorrow, in their lives. In a later study, Hainsworth (1996) conducted interviews with and administered the Burke/NCRCS Chronic Sorrow Questionnaire (caregiver version) to a convenience sample of 10 subjects who were spouses and primary caregivers of people with multiple sclerosis. Eighty percent of the caregivers were found to experience chronic sorrow.
Participants also identified coping strategies and gave advice for nurses and other healthcare providers.

In seminal chronic sorrow research, Eakes, (1993) conducted structured interviews using the Burke/NCRCS Chronic Sorrow Questionnaire with 10 individuals with cancer diagnoses and found 9 out of 10 exhibited signs of chronic sorrow. In a subsequent study using the same instrument (caregiver version) but a new population, Eakes (1995) sought to understand the lived experience of parents caring for mentally ill children. She used a convenience of ten parents and found chronic sorrow in eight of them. Participants described these grief-related feelings as being triggered by unending care responsibilities.

The Burke/NCRCS Chronic Sorrow Questionnaire in several versions has been used to reveal chronic sorrow in persons with Parkinson’s disease and their spouses (Lindgren, 1996), parents of children with neural tube defects (Hobdell, 2004), parents of children with epilepsy (Hobdell, Grant, Valencia, Mare, Kothare, Legido, & Khurana, 2007), and people living with multiple sclerosis (Isaksson, Gunnarsson, & Ahlström, 2007).

Other researchers have used different methods and instruments. Damrosch and Perry (1989) mailed an original survey to 25 sets of parents of children with Down’s syndrome. Eighty-three percent of fathers reported a slow steady adjustment while 68% of mothers reported signs of chronic sorrow. Hummel (1991) used a questionnaire developed by Fraley (1990) to survey 103 parents of 61 children. Hummel identified feelings including chronic sorrow, helplessness, frustration, and self-blame.
Phillips (1991) employed a case study model to examine the lived experience of three mothers caring for chronically ill children. The researcher concluded that time may be a crucial factor in the development of chronic sorrow because the certainty and permanent nature of the condition needs time to evolve. Interestingly, Phillips also found that denial may preclude the development of chronic sorrow.

Northington (2000) employed a grounded theory approach with a convenience sample of 12 African-American caregivers of children with sickle cell disease. This study showed that diagnosis has an immediate and profound effect on caregivers, chronic sorrow becomes increasingly evident over time, and feelings of powerlessness ultimately lead to a state of “doing what you have to do and moving on.” (p. 141).

Lichtenstein, Laska, and Clair (2002) conducted narrative interviews and administered the Center of Epidemiological Studies on Depression Scale (CESD) to assess for chronic sorrow in HIV positive persons. The research revealed that more than half of the subjects scored as depressed, with African American women scoring significantly higher than white men or women. Antle, Wells, Goldie, DeMatteo and King (2001) conducted qualitative interviews with 105 parents caring for 157 children to understand the experience of parenting in families living with HIV/AIDS. All 77 of the mothers, 22 fathers, and 17 children were HIV positive. Chronic sorrow, stress and burden, normalization, stigma, secrecy, and disclosure emerged as themes. Scornaienchi (2003) conducted a family case study of one mother with two children with lissencephaly, a rare and terminal genetic condition in which a child is born without the brain folds and convolutions, with severe neurological impairment. In this case, the mother also experienced great moments of joy and developed a cognitive style of coping.
in which she learned as much as possible about the disorder and potential interventions. Ahlström (2005) undertook a qualitative study using two interviews with 30 people with chronic illness. Sixteen of the 30 were assessed to have chronic sorrow.

The literature also contained some autobiographical accounts of personal experience with chronic sorrow. Hollingum (1995) recounted her own understanding of this phenomenon as it developed after the birth of a son with a genetic immunity disorder. Kraft and Kraft (1998), both doctorally prepared healthcare providers, described their 32-year experience of caring for their son who was born normal but developed profound mental retardation over time related to intractable seizures. Rosenberg (1998) described how chronic sorrow affected the life of her father as lived with his diagnosis of prostate cancer. Caitlin (2003) documented the murder of two adult children with advanced Huntington’s disease by a mother who was experiencing chronic sorrow.

In summary, chronic sorrow has most often been described as a phenomenon experienced by caregivers of a person with illness or disability but it also has been found in people diagnosed with illness. I wondered whether chronic sorrow might be experienced by people diagnosed with bipolar disorder perhaps as a result of an associated inability to fully achieve developmental milestones or life expectations.

Uncertainty

Uncertainty can be defined as “a cognitive state resulting from insufficient cues with which to form a cognitive schema, or meaning of a situation or event” (Bailey, Wallace, & Mishel, 2005, p. 735). People with chronic disease or people caring for significant others with chronic disease may experience uncertainty as an important and
common experience in addition to grief, loss, and chronic sorrow. This phenomenon has been reported to increase the distress and suffering of persons with chronic illness and it is thought to potentially influence ultimate prognosis among disparate patient populations (Brashers, Neidig, Reynolds & Haas, 1998).

In one early investigation, Mishel and Braden (1987) used a correlational descriptive design to assess the influence of uncertainty and optimism in adjustment to chronic illness among women with gynecological cancer. They administered the Norbeck Social Support Questionnaire, Mishel Uncertainty in Illness Scale, and the Psychosocial Adjustment to Illness Scale to a convenience sample of 44 women. The researchers concluded that people may experience a personal awareness that the presence of a stable core of available and supportive people can reduce uncertainty and relieve distress.

The relationship of uncertainty and quality of life was examined by Padilla, Mishel, and Grant (1992) in a quantitative study of 100 women with cancer. The subjects completed multiple scales. With regard to uncertainty, the study demonstrated the more positive the attitude about the outcome coupled with problem-based coping and perceived mastery, the less the uncertainty.

The Padilla et al. (1992) findings were confirmed in subsequent research. Bailey, Wallace and Mishel (2005) conducted a qualitative descriptive investigation in which they interviewed 10 men who opted to monitor their prostate cancer progress rather than undergo immediate treatment intervention. The results indicated that uncertainty arose in all of the subjects leading the researchers to conclude that nurses and other healthcare providers might need to examine their role in helping to manage uncertainty. Sanders-Dewey, Mullins, and Chaney (2001) studied 44 dyads of people with Parkinson’s disease.
and their caregivers in a correlational study and found higher levels of problem-focused coping and perceived uncertainty in illness were associated with increased caregiver distress.

Also, Wineman, Schwetz, Zeller, and Cyphert (2003) investigated illness uncertainty, coping, hopefulness, and mood experienced by a convenience sample of 52 people who were participating in a drug trial testing a new multiple sclerosis medication. Participants with greater uncertainty about their disease were likely to experience less hopefulness and more negative moods.

In summary, bipolar disorder has a fluctuating trajectory and perhaps a certain degree of uncertainty due to the trial and error approach needed to find effective treatment. I wondered whether people diagnosed with bipolar disorder experience uncertainty and if it has any impact on daily life.

Self-transcendence

Self-transcendence is “the ability to look beyond self and present difficulties, to extend concern to others, and to find personal meaning and wholeness in the context of changing life events” (Acton & Wright, 2000, p. 144). A definition is “the capacity to extend personal boundaries multi-dimensionally and to be oriented toward perspectives, activities, and purposes beyond the self without negating the value of self” (Upchurch, 1999, p. 253). Chronic illness does occur, nonetheless, some people seem to successfully cope with it and adapt, perhaps involving the process of self-transcendence.

Frankl (1992, 1954), an Austrian psychoanalyst held in prison camps during World War II, claimed searching for life’s meaning is a person’s primary motivation.
Later research (Upchurch, 1999; Acton & Wright, 2000, Ellermann & Reed, 2001; and Acton, 2002) investigated how finding meaning contributed to self-transcendence and finding moments of health or wellness within the context of having chronic or terminal disease.

Lindsey (1996) conducted an interpretive phenomenological study of eight participants living with a variety of chronic conditions. Six themes emerged: a) honoring the self, b) seeking and connecting with others, c) creating opportunities, d) celebrating life, e) transcending the self, and f) acquiring a state of grace. These themes called for a reevaluation of how illness and living with illness are viewed. Upchurch (1999) studied 88 elders in a non-probability purposive design and found significant positive relationships between self-transcendence, health status, and the ability to perform activities of daily living. Ellerman and Reed (2001) examined the relationship of self-transcendence and depression in 133 depressed middle-aged people and found a significant inverse relationship between the two variables. Fredriksson and Linstrom (2002) who interviewed hospitalized people with chronic psychiatric illnesses, also suggested that finding meaning in chronic illness played as important a role in coping as problem-based or emotion-based strategies. The literature included no studies of self-transcendence behaviors by people diagnosed with bipolar disorder, but I speculated a link might exist.
A comprehensive review of the literature revealed that people living with bipolar disorder are an under-researched population. The lived experience investigations by Driscoll (2004) and Jönsson, Wijk, Skärsäter and Danielson (2008) investigation were the only two identified. The current investigation contributes by adding to the understanding and knowledge of this under-researched population—persons with bipolar disorder.

The existence of chronic sorrow, uncertainty, and self-transcendence has been well documented in other populations with chronic disease. These phenomena may indeed exist but have not, as yet, been identified or studied in persons with bipolar disorder. This investigation sought to determine if these phenomena also exist in persons living with bipolar disorder. In addition, the literature does not describe the role, if any, of spirituality among people diagnosed with bipolar disorder. This study also attempted to add to that understanding.
CHAPTER 3

METHODOLOGY

Introduction

Chapter Three discusses the qualitative research methodology used in this investigation with an emphasis on a “phenomenological hermeneutical method” described by Lindseth and Norberg (2004). First, the suitability of a qualitative approach for this exploration of people living with bipolar conditions is considered. Then the methods, including the sampling strategy, informed consent process, data collection tools, recording and storing data, risks and costs to participants, interview process, and data analysis procedures are discussed.

As shown by the literature review, the prior research primarily sought to discover the impact of having bipolar disorder on specific aspects of one’s daily living (e.g. employability or medication adherence). As a nurse, I desired to take a more person-centered view. The American Nurses Association (ANA, 2010) asserts that professional standards compel nurses to assess and intervene in a holistic fashion that includes how a person thinks and feels about his or her disorder. That stance underpins this research.

This investigation, thus, was a broader exploration of living with bipolar disorder, which examined the effect of this condition on the cognitive, affective, and spiritual domains of one’s life. Although it is artificial to separate these domains, for the purposes of this investigation the cognitive domain was defined as those activities related to how one knows, thinks, or perceives phenomena in a way distinct from emotion. The affective
domain referred to the feelings and emotions associated with phenomena that are distinct from cognitive reasoning or knowledge. The spiritual domain was defined as those sacred or holy related values, attitudes, and beliefs that are distinct from cognitive and affective elements.

Method

A phenomenological approach is well-suited to this investigation of lived experience (Graneheim & Jansson, 2006; Kowlessar & Corbett, 2009; Patton, 2002). Such an approach seeks to find the essential meaning or essence of a particular phenomenon for a person or group of people (Patton, 2002). Using this technique, the researcher attempts to gain a deeper understanding of a lived experience (Patton, 2002) in order to share it with others who seek better understanding of the phenomena.

Lindseth and Norberg (2004) developed a variation on general phenomenological approaches by describing techniques for interpreting interview texts obtained in healthcare research, which they termed a “phenomenological hermeneutical method.” I did not adopt their theoretical framework in full but borrowed from the analysis strategy because it was well suited to interpreting lived experience data. The strategy has been tested in multiple studies mostly conducted in Sweden by Lindseth and colleagues (Sørlie, Lindseth, Forde, & Norberg, 2000; Sørlie, Lindseth, Forde, & Norberg, 2001; Stigsdottir-Nyström & Nyström, 2007). Basically, the method entails reading the interview transcripts to first obtain a naïve and overall understanding. Then, meaning units are identified and condensed into themes and sub-themes. The themes are
reconsidered in comparison to the investigator’s naïve understanding and the relevant literature. Figure 1 illustrates the analysis process.

Sampling and Recruitment Strategy

A convenience sample of approximately 10 participants was planned for the research. More specifically, sampling was to continue until data saturation was accomplished or 10 complete interviews were obtained. Because portraying the full spectrum of people living with bipolar disorder is beyond the size and scope of this investigation, the number of 10 participants was selected in part to meet practical constraints. It also was consistent with the sample size used in similar phenomenological investigations (Sørlie, Lindseth, Forde, & Norberg, 2001; Graneheim, & Jansson, 2006).

I was unable to recruit 10 participants, however, despite prolonged and varied efforts. Due to time constraints, therefore, participant recruitment and interviews were concluded after eight completed interviews were obtained.

A classified advertisement (Appendix A) was placed in a general metropolitan area daily newspaper and a weekly newspaper published by a public university with the purpose of soliciting telephone or email participant inquiries. Due to limited response, the advertisement was subsequently placed in an informal alternative publication, and flyers were also posted in public spaces.

Inclusion criteria were described in the advertisement, flyers, and a follow up screening conversation as the need for participants to be: 18 years of age and older, fluent English-speaking, able to participate in a single one- to two-hour interview in a particular
1. **Creation of Texts** - The transcriptions of audio files and case notes into Microsoft Word® provided the data for this study.

2. **First Analysis Step**, a naïve reading of the transcripts was done. A naïve reading is accomplished by reading all the transcribed texts to obtain a general sense of their meaning. The investigator then reads each text a number of times in order to further grasp its meaning as a whole (Graneheim & Jansson, 2006).

3. **Second analysis step.** Meaning units were isolated. The next step was the structural analysis that attempted to establish themes (Graneheim & Jansson, 2006). A theme “is a thread of meaning that penetrates text parts, either all or just a few.”

4. **Third analysis step.** The next step was to construct a comprehensive understanding (Lindseth & Norberg, 2004). The themes and sub-themes were summarized and examined in relationship to the research question, the context of the study, and relevant literature.

5. **Final analysis step.** Finally, the results were written in everyday language as close to the lived experience as possible. The researcher compared his results to his naïve understanding of the original transcripts to assure congruence with the original participant responses.

*Figure 1. Analysis Procedures*
Midwestern city, and willing to give written consent for study participation. A decision to limit subjects to those who had been diagnosed for at least one year was based on the presumption that an ability to describe the lived experience of a cyclical affective disorder was, at least in part, dependent on living for a minimum of one year with the disorder.

Exclusion criteria were not expressed in the recruitment literature but they included evidence that respondents who were unable to remain engaged and focused during the pre-interview consent stage or in the data collection interview. If such cases occurred, the investigator planned to thank them for their interest, but decline to interview them. This did not occur in the current investigation.

Informed Consent Process

Approval of the protocol of this investigation was obtained from the Human Subjects Institutional Review Board at Western Michigan University following full board review. Potential participants received a verbal explanation of the interview process at the beginning of the face-to-face interview meeting. Potential participants were informed about the areas to be covered in the interview and the interview procedure. They were given opportunity to review and sign the investigation consent form (Appendix B) prior to completing the demographic questionnaire (Appendix C) and beginning the data collection interview (Appendix D). Ten people responded to the recruitment literature and eight individuals who responded to the recruitment literature consented to participate.
Data Collection Tools

The interviews were conducted using open-ended questions followed by appropriate contingent questions and further probes. An original 20-item interview guide (Appendix D) was constructed for this investigation to provide a starting point to elicit participant responses from which essential meanings could emerge. The guide was influenced by Lindseth and Nordberg’s (2004) phenomenological method and the Burke/Nursing Consortium for Research on Chronic Sorrow (NCRCS) Questionnaire. The former uses broad opening questions to elicit data, whereas the latter specifically searches the affective experience through open-ended queries. As previously noted, the research method developed by Lindseth and Norberg (2004) has been used in numerous and varied lived-experience investigations (Delmar et al., 2006; Lundman & Jansson, 2007; Sørlie, Lindseth, Uden & Norberg, 2000; Lindseth, Jacobsson, & Norberg, 1999). The Burke/NCRCS Questionnaire as been used to detect and describe chronic sorrow in multiple studies (Burke, Hainsworth, Eakes & Lindgren, 1992; Eakes, 1995; Hainsworth, 1996; Lindgren, 1996; Hobdell et al., 2007; Isaksson, Gunnarsson & Ahlstrom, 2007).

A Global Assessment of Functioning (GAF) score was determined as an estimate of each individual’s overall level of functioning at the time of the interview. I used this scale as a measure to assess participants’ ability to participate in the interview and to screen for symptoms. I believed this assessment was an important component to preserve patient safety. The scale is divided into 10 ranges of functioning. Each range has two components: symptom severity and functioning. This GAF score was determined by me, the researcher who earned a Master’s Degree in Nursing as a clinical nurse specialist and
had, at the time of the interviews, more than 29 years of medical/surgical and mental health nursing experience. I also had been teaching mental health nursing for seven years.

After enrollment, participants were asked to complete an eight-item demographic questionnaire prior to the start of the formal interview. The demographic information regarding race and ethnicity, age, gender, children, education level, and approximate yearly income was necessary to provide a context to the participants' interview responses.

Data Collection Procedures

The single interview with each participant in the proposed study was planned to take place in a private college library conference room or another mutually approved location other than the investigator’s academic office. Four of the eight intervals were conducted in the library conference room, a small room with windows off a main hallway. Another interview took place in a conference room in another building because the library was closed. The remaining two interviews were conducted, at participant request, at the dining room table in their homes.

The design allowed for second interviews to be scheduled if needed to obtain clarification of initial information. No second interviews were deemed necessary. I neither met nor spoke with the participants after the interview.

When conducting the interview, I encouraged each participant to tell his or her story as fully and freely as possible. I posed questions from the guide and then followed with contingent probes such as, “You mentioned ---. Tell me more about that,” “How do you feel about that?”, and “Can you elaborate about that experience?” Questions and
follow-up probes were used until the topic of living with bipolar disorder was fully explored. At times, I also wrote brief field notes at the time of the interview or immediately following the interview that detailed any impressions and observations of non-verbal behaviors.

Recording and Storing the Data

The interviews were recorded using two digital recorders, with the second serving as a backup measure. Interview audio files were transferred to a protected PC hard drive. I transcribed the recordings and field notes into Microsoft Word® using Express Scribe®. The password-protected audio and transcription computer files, backup computer disc files, and original field notes were stored in a locked private office.

Risks, Costs to, and Protections for Subjects

Potential parking fees, depending on where participants chose to park for the interview, were the only anticipated costs likely to be incurred by participants. As an incentive and partial compensation for their efforts and time, respondents were told they would receive a $25 gas gift card on completion of the interview in appreciation for their participation. Psychological distress or harm was not anticipated but it was noted it could arise due to recurrent sadness or anxiety evoked by the interview process. As protection, prior to the interview, participants were clearly informed of their option to terminate the interview at any time. They also were told that I might elect to terminate the interview at any time if it appeared to be in anyone’s best interests. If pronounced symptoms or feelings of distress arose that did not abate after the interview was terminated, or if a
participant scored low on the GAF scale and exhibited other symptoms, the plan was to strongly encourage participants to contact their personal health care provider or Ingham County Mental Health Emergency Services at 517-372-8460 or the Listening Ear Crisis Center at 517-337-1717. I was also prepared to support participants in their efforts to access treatment. All participants were given this contact information even if not experiencing feelings of distress.

Some participants became tearful for brief moments as they described difficult and distressing prior life experiences, but no crises occurred and no participants appeared distressed by the end of the interview. One participant did score 40 on the GAF scale due to constant auditory hallucinations. However, the participant reported hearing these voices constantly for the past 10 years and functioned at higher levels in all other respects. After the recorders were stopped following each interview, the researcher asked the participant how he or she was feeling. All participants responded they were feeling fine and exhibited a congruent affect.

Analysis Procedures

Bracketing

Phenomenology attempts to answer the fundamental question: “What are the meanings, structures, and essences of the lived experience of this phenomenon for this person or group of people?” (Patton, 2002, p. 104). Each researcher has, through life experience and reflection, gained a nuanced perspective of how she or he perceives and interacts with the world. This makes total objectivity impossible, but total objectivity, however, is not the goal of bracketing. My interest in mental health and concern for those
diagnosed with bipolar disorder led me to undertake this study. My experience as a mental health provider evoked an empathetic interest in people living with bipolar disorder and my therapeutic communications skills gained in clinical practice aided data collection. Thus, it is not advisable for the researcher to bracket all past experiences, and knowledge. However, in some qualitative research, researchers are expected to make sincere efforts to put aside or “bracket” the values, attitudes, biases, and beliefs that would overshadow phenomena as experienced by participants (Ahern, 1999). Ahern also indicated it is important for a researcher to integrate specific bracketing strategies within an investigation (Ahern, 1999). Bracketing is a means of enhancing the trustworthiness of the data collection and analysis process.

My professional background as a clinician includes delivering medical/surgical and mental health nursing care to inpatients (critical care and basic medical/surgical units, adult and geriatric psychiatry units) and outpatients (primarily home care visits to medical and mental health clients) for nearly three decades. As a researcher, I sought to hold in abeyance any presuppositions regarding living with bipolar disorder that I may have acquired throughout my career as a health care provider and nursing educator. I attempted to bracket my own knowledge and internal suppositions of bipolar disorder and the life ways I had observed past patients employ. For example, I recall former patients diagnosed with bipolar disorder who frequently needed acute hospitalizations due to non-adherence to medications. I also recognized my knowledge of the stigma associated with mental health disease as an ever-present reality for past patients. I remained aware of my past experiences but fully listened to the participants’ description of their experiences.
In addition, it was important for me to recognize my presuppositions regarding uncertainty, chronic sorrow, self-transcendence, and spirituality. As has been previously described, I found literature that described these phenomena as being associated with chronic illness. I also recall parents of former patients (e.g., young people with closed-head injuries) describe feelings that I would now term “chronic sorrow.” I understood that I needed to be aware of these experiences but not expect they emerge in the current investigation.

I needed to be aware that my own spiritual practices are not typical for most people and to use that awareness to accept the validity of participant spiritual beliefs and practices. In addition to being a nurse, I am a professed Brother of Penance in the Roman Catholic Secular Franciscan Order (SFO) and I am actively engaged in contemplative and lay ministry efforts. The SFO was the “third order” founded by St. Francis of Assisi in the early 13th century. The “first order” included St. Francis and the brothers that ministered with him. The “second order” included St. Clare and the sisters who ministered and lived with her. The SFO is open to all Catholic lay men and women and ordained deacons and priests who complete preparations provided they are not professed members of another order. The SFO brothers and sisters “profess”, after two years of study and discernment, to live Jesus’ teachings and bring the Gospel to life by following in the footsteps of St. Francis. The SFO brothers and sisters engage in penitential practices, public ministry, detachment from riches, a structured prayer life, following a prescribed rule, and obedience to His Holiness the Pope. Although, my spiritual beliefs and adherence to a religious rule led me to have great empathy and love for the participants, it was important that I, as a researcher, recognized my need to “bracket” my
own spiritual beliefs and practices in order to fully attend to participants who might
describe beliefs and values different from my own.

Reflexive Journal

Prior to the start of an investigation of this nature, a researcher is advised to begin
a reflexive journal in which to clarify his own values and acknowledge areas of
subjectivity, describe potential areas of role conflict, and recognize feelings that indicate
a lack of neutrality (Ahern, 1999). The journal should be maintained throughout the
investigation and continue through the analysis phase because questions often arise.
Ahern (1999) states these queries include, “Are you quoting more from one respondent
than another?” If one is, one needs to ask why. For example, does one agree with a
particular person’s sentiment or turn of phrase more than those of another or is a
particular participant merely more articulate and engaging than another?

I maintained my bracketing efforts throughout the research by using such a
reflective journal. In journal entries, I recorded the processes used in methodological
decision making, and input based dissertation committee discussions. I included personal
thoughts and feelings that emerged during interviews, my reflections about those
thoughts and feelings, and the meanings and interpretations that arose from those
reflections.

Creation of Texts

Interview texts were created through transcription of the interaction between the
interviewer and interviewee. The interviews took place in a shared context; both partners
had an understanding of the research purposes of the interview situation. This has advantages over asking participants simply to write their responses, as narrative or on a survey form, because during an interview, the investigator has the opportunity to validate and clarify his or her perceived understandings (Lindseth & Norberg, 2004). The transcripts of audio files supplemented by case notes and journal entries also transcribed into Microsoft Word® provided the data for this study. I chose to analyze the data manually rather than use a specific analytical software product due to the small number of participants and the desire to immerse myself more fully in the data.

Data Analysis

The interview texts were created through transcription of the interaction between the interviewer and interviewee. The interviews took place in a shared context; both had an understanding of the research purposes of the interview situation. This has advantages over asking participants simply to write their responses, as narrative or on a survey form, because during an interview the investigator has the opportunity to validate and clarify his or her perceived understandings (Lindseth & Norberg, 2004).

First Analysis Step

First, a naïve reading of the transcripts was done. A naïve reading is accomplished by reading all the transcribed texts to obtain a general sense of their meaning. The investigator then reads each text a number of times in order to further grasp its meaning as a whole (Graneheim & Jansson, 2006). Using this technique, the reader allows the text to "speak" to him or her and perhaps, to be moved by it. In using this
technique, I made the effort to switch from a natural attitude to a phenomenological one in which the naïve understanding was recorded in phenomenological language that consisted of initial general phrases intended to capture the meaning and essence of the text (Lindseth & Norberg, 2004). I highlighted these areas and inserted comments using features of Microsoft Word ®. These findings were reviewed by the four members of the dissertation committee to assess the accuracy of my naïve understanding. The naïve understanding developed in this stage established a background to guide the second step.

Second Analysis Step

The second step was the structural analysis used to establish themes (Graneheim & Jansson, 2006). Lindseth and Norberg (2004) recommended a thematic structural analysis in which the investigator attempts to identify and formulate themes. A theme “is a thread of meaning that penetrates text parts, either all or just a few” (Lindseth & Norberg, 2004, p. 149). The goal is to capture the essential meaning of the lived experience. In performing this step, I first read the transcripts and divided the texts into meaning units. A meaning unit is a portion of text of any length that conveys a single meaning (Graneheim & Jansson, 2006). It may comprise a part of a sentence, a full sentence, several sentences, or a paragraph. Some parts of the text that had no relationship to the research question (e.g. comments about the weather, finding parking) were transcribed and considered but they were not used in forming meaning units or themes.

During this second structural analysis step, it was crucial to view the text as objectively as possible (Sørlie, Lindseth, Uden, & Norberg, 2000; Lindseth & Norberg,
That is, I considered the text parts as independently as possible from their context. This is possible if the meaning units contain only one meaning. When I found more than one meaning in the meaning unit, I further subdivided the participant quote until each segment contained only one meaning.

All meaning units were read and considered against the context of the naïve reading (Graneheim & Jansson, 2006). Then they were condensed so that “the essential meaning of each meaning unit was expressed in everyday words as concisely as possible” (Lindseth & Norberg, 2004, p. 150). All condensed meaning units were examined for similarities and differences and then sorted into sub-themes that were then reassembled into themes.

A five-columned template (Appendix E) was used to organize this second analysis step. The first column specified a location code describing the entry’s transcript location into the first column. The second column contained meaning units that were direct quotes from the participant responses. The third column was used to record my naïve understanding as condensed basic meanings. The fourth column included the condensed meanings reduced to sub-themes. The fifth column was used to collect the sub-themes into general theme categories. The findings were presented to the members of my committee for review and discussion. The interpretation process was refined during these discussions to enhance congruence to the original participant comments.

Third Analysis Step

The next step was to construct a comprehensive understanding of the findings (Lindseth & Norberg, 2004). The themes and sub-themes were summarized and
examined in relationship to the research question, the context of the study, and relevant literature. The text was read again as a whole remaining mindful of the naïve understanding and the interpreted themes. The focus, in this step, was on understanding the world opened up by the text (Sørlie, Lindseth, Uden, & Norberg 2000; Graneheim & Jansson, 2006). Lindseth and Norberg (2004) noted that researchers tend to interpret out of their “preunderstanding” and they are only aware of some aspects of those influences. However, through careful, critical reflection, researchers can broaden their awareness. I attempted to follow that advice in this investigation.

In this inquiry, I used another template (Appendix F) to aid identification of final themes experienced by participants with regard to cognitive, affective, and spiritual domains. The first column identified 22 particular realms of daily experience such as friendships, employment, circumstances surrounding diagnosis, treatment, and so on. I entered transcript location codes for participant meaning units relevant to the cognitive domain in the second column. Transcript location codes for affective and spiritual domain responses were also respectively inserted in the third and fourth columns. Brief notes used to sort data were recorded in the fifth column.

Final Analysis Step

Finally, the results were written in everyday language as close to the lived experience as possible. These results are presented in Chapter Four. I attempted to follow the advice that the interpretation of a text is more apt to reflect the participant’s lived experience if it is the one that makes the most sense using the greatest number of details from the text and extracts all that can be discovered in the text (Lindseth & Norberg,
I then compared the results to my naïve understanding of the original transcripts to assure congruence with the participant original responses.

Methods Summary

In summary, this investigation used a phenomenological approach that involved conducting open-ended interviews with adult English-speaking men and women who had been diagnosed with any of the three forms of bipolar disorder for at least one year. Participants completed a demographic questionnaire prior to the interview and a Global Assessment of Functioning score was determined during the interview by the researcher.

The demographic data provided a context for interpreting the data obtained through the interview process. The GAF score helped to assess the ability of participants to safely participate. The interview audio recordings and the investigator’s field notes were transcribed into Microsoft Word®. The resultant transcripts underwent a naïve reading, structural analysis, and then a reconstruction to provide a comprehensive understanding that was examined in the context of the research question, relevant literature, and the participants’ responses.
CHAPTER 4

RESULTS

Introduction

Chapter Four reports the results of this investigation. It begins with a discussion of the demographic characteristics of the eight participants. Then, a discussion of the four themes that emerged during data analysis follows. A summary of key findings concludes the chapter.

Participant Demographic Information

Eight people responded to recruitment materials and agreed to be interviewed in this investigation. Interviews lasted for approximately one hour and ranged from 54 to 75 minutes. No potential participants were screened out. Due to the small number, the demographic data are presented here in the aggregate rather than a more detailed fashion as an effort to preserve participant confidentiality and anonymity (see Table 1). Seven of the participants were female. Six participants self-identified as White and one each as Black and Other. There were no Hispanic participants. The self-reported age at the time of the interview ranged from 19 to 43 years with a mean and median of 31.4 and 31 years respectively.

The self-reported age of diagnosis with bipolar ranged from 13 through 38 with a mean of 24.3 years. The length of time since diagnosis ranged from two through 12 years with a respective mean and median of 7.3 and 7.5 years. Two people had been diagnosed
Table 1

Demographic Summary of the Eight Participants

<table>
<thead>
<tr>
<th>Category</th>
<th>Data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>7</td>
</tr>
<tr>
<td>Male</td>
<td>1</td>
</tr>
<tr>
<td>Age Range</td>
<td>19 to 43 years</td>
</tr>
<tr>
<td>GAF Range</td>
<td>40 to 90</td>
</tr>
<tr>
<td>Age at Diagnosis Range</td>
<td>13 to 38 years</td>
</tr>
<tr>
<td>Length of Diagnosis Range</td>
<td>2 to 12 years</td>
</tr>
<tr>
<td>Self-reported Race</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>6</td>
</tr>
<tr>
<td>Black</td>
<td>1</td>
</tr>
<tr>
<td>Hispanic</td>
<td>0</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
</tr>
<tr>
<td>Approximate Yearly Income Range</td>
<td>$17,000 to $60,000</td>
</tr>
<tr>
<td>Highest Education</td>
<td></td>
</tr>
<tr>
<td>High School</td>
<td>1</td>
</tr>
<tr>
<td>Some college or Associates Degree</td>
<td>3</td>
</tr>
<tr>
<td>Bachelor's Degree</td>
<td>4</td>
</tr>
</tbody>
</table>
for two years and two other participants had been diagnosed for 10 years.

Global Assessment of Functioning (GAF) (APA, 2000) scores were determined by the investigator based on interaction with the participants. Scores ranged from 70 to 90 for all but one participant who scored 39-40 because of persistent auditory hallucinations. The participant with the single low score experienced constant auditory hallucinations (i.e., heard voices) but was able to recognize the voices as a symptom of his illness and reported that hearing voices was a constant experience for the past ten years. He was, however, able to remain engaged in the interview; his mood and affect were congruent; and, aside from some paranoia that he recognized as a symptom of his illness, his thoughts were organized and goal-directed. On the GAF axis, scores in the 70s indicate the presence of transient and expected symptoms in response to stressors. Scores from 81 to 90 reflect absent or minimal symptoms and good functioning in all areas.

Two participants declined to respond to the question about income but the others reported an approximate yearly income from $17,000 to $60,000 with a mean of $35,833. The highest level of education ranged from high school graduate (one person) through bachelor’s degree (four people). Three reported some college or an associate’s degree. Seven participants reported past or present diagnosis of co-morbid disorders. These reported co-morbid conditions included post partum depression, anxiety, major depression, stereotypical movement disorder, tactile defensive disorder, schizophrenia, diabetes, and cardiomyopathy. All participants reported being prescribed medications for bipolar disorder but two of the women were pregnant at the time of the interview and each of these had been told by their medical providers to stop their bipolar medications
for the duration of their pregnancy due to their teratogenic properties. A third person was not taking medications at the time of the interview because of adverse effects on comorbid conditions. Five participants indicated current use of anti-depressant, mood stabilizing, and/or antipsychotic medications. Four of the eight participants disclosed a history of suicide attempts.

Analysis Process

I first undertook a naïve reading of all the interview transcripts. My initial impression was recognition of the articulate and emotion-laden nature of the stories shared by the participants. Two of the participants were pregnant at the time of the interview and not taking medications. Both exhibited mildly labile moods and pressured speech. As noted previously, one person was also diagnosed with schizophrenia and reported hearing voices. I observed this participant demonstrated paranoid ideation as evidenced by frequent references to his perceptions that health care providers and family members purposefully treating the participant badly. I read through the transcripts multiple times and formed some initial understandings including that relationships between participants and those they cared about could be sources of distress or comforting. Each participant had definite opinions about providers and treatments. Each participant told emotion-laden stories about the circumstances surrounding their diagnosis with bipolar disorder. Although each person had unique life experience, they all shared some universal feelings and common experiences.

The process then involved identifying individual meaning units contained in the participants’ stories and condensing them into themes and subthemes. A sample of this
process is illustrated in Table 2. I summarized the themes and evaluated them for congruency with my naive understandings, the research question, and the literature. I also found some participant perspectives that had not been described in prior research. These are discussed below. The four themes that emerged during data analysis include the following:

1. Diagnosis brings understanding accompanied by irrevocable change,
2. Finding effective treatment is an interminable process,
3. Bipolar disorder is the third partner in every relationship, and
4. Caring for oneself is as important as receiving formal treatment.

Each of these themes is discussed below and illustrated by participants’ comments.

Theme One: Diagnosis Brings Understanding Accompanied by Irrevocable Change

I asked participants to describe the circumstances surrounding their diagnosis with bipolar disorder. Each of the participants was able to identify a specific time when the bipolar diagnosis was given by a psychiatrist. Most participants, however, referred to the actual diagnosis as an event that occurred long after symptoms manifested. Diagnosis, it appeared, gave meaning to past experiences for many. Rita (all names are pseudonyms), was age 42 at the time of the interview and had been diagnosed at age 33. She expressed thoughts shared by the other participants when she said:

It kind of clicked into place. Like, this explains a lot of my past behavior and my life situations and the situations I’ve gotten and not gotten in to. It kind of put a piece into the puzzle. At first, it was kind of hard to accept but then it was like you know—this makes sense. It makes total sense!
**Table 2**

Sample of Stage 2 Analysis

<table>
<thead>
<tr>
<th>Location</th>
<th>Meaning Unit</th>
<th>Condensation to a basic meaning</th>
<th>Sub-themes will be assembled into themes</th>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>7c</td>
<td>Other than that, I had a great social life at that time...maybe a greater than great social life than I should have had....maybe that was the cause of it also. But actually, my life at that point was very, very, good - compared to what it is now.</td>
<td>My life was very good compared to what it is now.</td>
<td>Life was good</td>
<td>Feeling life was good but then changed for the worse</td>
</tr>
<tr>
<td>9a</td>
<td>Now it is a lot worse. It's like my life took a nose dive. Over the years, my symptoms have gotten worse. Um, I'm more isolated now. I'm more reserved....I don't want to get close to people.</td>
<td>My life took a nose dive. My symptoms have gotten worse with time. I don't want to get close to people.</td>
<td>Life changed for the worse</td>
<td>Feeling life has worsened</td>
</tr>
<tr>
<td>9b</td>
<td>I don't want to talk to a lot of people. I say to myself....so, I guess these are just symptoms maybe of my disorder</td>
<td>I guess these are symptoms of my disorder</td>
<td>Uncomfortable around people</td>
<td>Feeling fear of people and comfort in isolating self</td>
</tr>
</tbody>
</table>
Sometimes diagnosis also brings a sense of relief. Jackie, age 34 at the time of the interview and diagnosed at age 32, remembered:

It was a relief because it explained a whole lot of stuff but at the same time, I was going to have to learn this new way of living! I realized that a lot of my life, what I thought was just ambition was probably mania...um, and the deep depressions I would get from time to time—I just thought depression just runs in my family and I just have my own depression.

Despite now being able to put past feeling and behavior into context, diagnosis did not always bring a sense of peace. Susan, who was age 19 at the time of the interview and diagnosed at age 13, reported:

When I was with my mom and we went to the doctor’s and that’s what they said. And then I go home and I tell my other mom and everyone’s like, finally we know what it is. It’s cured! But it is not! And I was feeling kind of left out in a weird way because...that’s it, you know, ‘cause I’ve got a label on me now and [people think] it’s going to be cured and all but it’s not. I still deal with it and I’m always going to.

Bailey, who was age 22 at the time of the interview and diagnosed at age 20, shared similar feelings:

It’s not like having this chronic cough and you don’t know what it is and you get a diagnosis...like, now I know how to treat it. It’s more like, oh great, now I have a diagnosis that doesn’t really have a definite treatment and it means I’m going to have these problems for the rest of my life so like....it sucks!

Gina, who was age 28 at the time of the interview and diagnosed at age 18, described a feeling shared by others when she reported:

I felt defective! This is still something I struggle with, um....that when it gets to the bad times I feel like I’m broken. Like I’m a broken person and because I don’t work right, my brain doesn’t work right, I um, can’t do the things that normal people get to do.

The above experiences demonstrate that diagnosis can bring one some understanding of perhaps inexplicable past behaviors, feelings, thoughts or other
symptoms however this cognitive understanding is accompanied by an affective response in which one also can experience a current sense of relief, or distress, or perhaps hopelessness. Participants also referred to experiencing these feelings of understanding, distress, and intermittent hopelessness at the time of the interviews as well as at the time of the diagnosis.

Diagnostic Process and Circumstances Are a Challenge

Participants reported that the journey to diagnosis was lengthy and seemingly serendipitous. People eventually diagnosed with bipolar disorder are sometimes initially diagnosed with and treated for other disorders, but when treatment fails to resolve or relieve symptoms the bipolar diagnosis was considered. Dora, who was age 25 at the time of the interview and 22 when diagnosed, described her experience:

"After so many antidepressants that didn’t work, finally they’re like—Oh you’re not just depressed, you’re bipolar. I was like….huh? [Laughs]. So, we went through all these medications, nothing worked, years later you tell me it’s because I’m bipolar?"

Gina had been treated with non-pharmacologic interventions for putative attention deficit hyperactivity disorder since early childhood. Gina reported her mother found that if she strictly structured Gina’s day, Gina would be less distracted and better able to accomplish required tasks. Gina also described one teacher who gave her assignment sheets that had been written backwards and upside-down. Gina reported the unusual format helped her focus and restrain her distractibility. She began medication treatment for depression at age 15. Gina described the circumstances surrounding her bipolar diagnosis as:
At age 15, I had a depressive episode—they put me on Prozac. Then, um, that worked fairly well for a while but then once the depressive episode abated a big one came back around. I went way down when I was 16. Then I had to be an inpatient because I had to be supervised. Then when I was 18, I attempted suicide and was an inpatient again......they put me on a combination of an antidepressant and a mood stabilizer. And the mood stabilizer was very effective in helping me get a foothold on my cycling. Um, and so, once that happened they diagnosed me as bipolar.

Sometimes symptoms exacerbated by pregnancy and childbirth compounded by avoiding medications, can lead to inpatient mental health hospitalizations. In cases where bipolar disorder has been previously undiagnosed, such circumstances could lead to the initial diagnosis of bipolar disorder. Jackie, who was diagnosed after recently giving birth to twins following an extremely complicated pregnancy, reported:

Um, I was in therapy for post partum depression and uh one day I went to my therapist and I was just losing it. An um, I ended up...she always told me that if it was time to go to the hospital, let her know....and I just said to her it is time to go to the hospital because I couldn’t handle raising two kids and the emotions that I was feeling. So, I ended up going to the hospital. And they diagnosed me as bipolar 1 and I was in a mixed state at the time. And once I got diagnosed, I mean, a whole bunch of stuff made sense [laughs].

Experiencing Bipolar Disorder

All participants indicated bipolar disorder is experienced not as a single disorder but rather two or perhaps three separate disorders - mania, depression, and/or mixed. Each of these three components is discussed and illustrated below.

Mania

A manic episode is identified by a discrete period lasting at least one week in which there is an abnormal and persistent elevated, expansive, or irritable mood (APA, 2000). The personal experience of mania differs among people. Some participants
reported that mania can be attractive to the person experiencing it. Jackie sat at her
dining room table during the interview, looking relaxed and thoughtful but laughed easily
and often. She was laughing as she began the following comments but subdued and quiet
at the end. Jackie said:

It all comes back to this thing when I turned 30, I just turned 30 and
graduated from college and that had been a whole mania thing for like two
years, I can see it now. Cause, most people don’t take 19 credits and work
two jobs......When I was manic I could get everything done!.....I feel
really good when I’m manic for about three days, then it’s just very hard
for me.

Sometimes the onset of mania is frightening. Gina reported her experience of
mania as:

I definitely feel out of control, the way I would explain it to my mom and
sister is....you know when you are on a roller coaster and the feeling that
you feel when you are about to go over the hill where...it’s that
anticipation of it and the fear of it except it’s not pleasant when it is an
emotional experience. When you are on the roller coaster its fun but it’s
not pleasant [when it is an emotion] because you know it is about to
happen, you are about to slip.....

At that time, Gina was smoking tobacco and using alcohol and marijuana to modify her
moods. She was involved in theatrical and literary circles. In her continued comments,
Gina said:

...there are moments when you are in your mania where you know it goes
from just being excited to being high energy and knowing what you are
doing to almost a compulsive, “I’ve got to keep going and doing things.”
And a lot of the time that would happen to me after two or three drinks
and you would go to the bathroom and look at yourself in the mirror and
you realize you have crossed that line from being out with your friends
and having a good time to, “I’m probably going to make some bad
decisions.” ....You know that it is that painful moment when you realize
that you’ve sort of left everybody else behind ...and you are on your own
in this really uncomfortable place—mania.
Cathy, age 43 at the time of the interview and 38 at the time of her diagnosis, was very succinct:

When I am in my manic moods from the bipolar, they’re not pretty either. I don’t have manic moods very often but...I’m...it’s just crazy for three or four days...I don’t sleep, I don’t eat, I don’t do a whole lot but my head is just going like crazy.

A common perception among non-health care providers might be mania is a pleasant high energy mood. Robert, who was age 38 at the time of the interview and diagnosed at age 26, described the beginning of his mania experience is fitting with that common perception that mania can be pleasant, but he noted that if often ends differently:

I’m like a Saturday Night Live standup comedian at times. Those are my manic states and I take it out on my brother and my mom. Honestly, actually, I feel really good, silly, goofy, happy but then again after I’ve done my little thespian spiel I’m like why in the hell did I do that? And it’s too late to take it back but...it’s me, this is who I am. I think it is something we need at home anyway so everything wouldn’t be so down and depressed. I calm down—actually, more than likely they will tell me to shut up and go sit down. I’ll shut up and go sit down. And then I will think about what I’ve said and what I’ve done and like....that was stupid, I shouldn’t have done that. But I do it all the time.....

Mania can include features other than enhanced energy and elevated moods. Manic episodes often include a spiritual component. As an example of this phenomenon, Bailey related:

When I was manic, I was extremely religious. I was sure God was telling me to do lots of important things. Um, and now, I’m not religious. For a while, after being sick for that time, I was like uh-uh [no] there’s no God!

Jackie, the recent mother of twins, also reported a sudden interest in religious practice. Whereas Bailey had intense religious interest only during mania, Jackie’s experience of mania intensified an already fervent spirituality that comforts her in daily life. She described her increased fervor during mania in this way:
Um, another thing that happened when I was manic was I thought I was called to be a priest. And it was my priest, I’m Episcopalian, it was my priest that um talked me down and said you may be a little bit manic right now. Which of course was very disappointing and of course he was right [amused laughter].

The previous discussion illustrates mania can be experienced as attractive or sometimes frightening episodes of increased energy, expansive mood, or impulsivity.

There is an aftermath to mania, however, that confronts the person who had been manic.

There is a sense of depersonalization such that one knows one behaved in particular ways but cannot reconcile that behavior with one’s personal sense of self or one’s values. The post-mania experience of attempting to repair damage resulting from behaviors during mania can be challenging. For example, Bailey shared:

I guess um...for me the hardest part was not any...its, very hard to be depressed. And it’s very, very hard to be manic. But after those, like collecting all the damage that you’ve done....when I was manic I spent loads of money. I racked up huge credit card debt. I did ridiculous things and now you are like....oh, I didn’t want to do that. You have to go and like pick it up...after that [it] is really hard. How do I explain to my grandparents who came to visit me that I’m not....I was sick. I was rude to them!! It was like out of control. And you don’t want to, like, hurt people like that and you wouldn’t on a regular basis but you’re not yourself. With mental illness you don’t have any.....I’m not missing a limb or don’t have bipolar on my head so...it’s hard.

Depression

Depression, at the other end of the mood continuum, can be experienced as reduced energy, depressed mood, loss of pleasure in things formerly held dear, and despair (APA, 2000). These experiences may not be perceived as abnormal. Jackie related:
I would have these periods where I would be laying on the floor and begging God to kill me.....and I thought that was normal....and it turns out [embarrassed smiles and chuckles] it’s not.

The participants reported self-isolation as part of the depression experience.

Often, only people closest to the depressed person understand what is happening. Gina said:

And when I get depressed, I withdraw and isolate myself. Only the very closest to me are familiar with my depressive episodes. Which now is my husband, mother, sister, and father,...my two brothers. It’s mostly just a family thing.

Depression evokes self-criticism and feelings of worthlessness. For example, Bailey explained:

Like, when you are depressed....it’s very hard for me, you’re very critical of yourself. I feel terrible all the time. I have no energy. I criticize myself by saying, “oh, everything’s fine you should have more energy. You have no reason to be depressed,” which only makes you feel worse about yourself….! It makes it hard to do really anything social…You just feel like not doing anything at all. You want to spend like 12, 14 hours in bed...you don’t do anything! You don’t want to take a shower, you don’t want to get up, you don’t want to do anything!

Feelings of sadness and powerlessness are exacerbated by the experience of being mentally ill. One participant, in particular, grieved the loss of the life that might have been. For example, Robert reported:

I had big dreams and aspirations. I wanted to get a PhD, maybe studying philosophy or...I even thought about being a medical doctor, um a physician. I do have an art background but I know that I do have a high IQ. Um, I was a gifted child. Very gifted. Um, but because of what has happened over the years it’s like, I don’t know, my brain has been wiped of all my information.

Cathy reported significant memory impairment that she attributed to multiple electroconvulsive therapy (ECT) treatments. However, she seemed to be able to describe
parts of her childhood and medical history in great detail. Her affect changed at this point in the interview. She had experienced a cognitive domain loss and grieved it. Cathy said:

That’s one thing that’s really bothersome about ECTs and the medications...a lot of my memory is gone [near tears, speech slow and deliberate]. I have lost so many memories. It’s...I hate to say it but I saw John Lennon’s picture on the front of a magazine and they talked about him being dead—I turned and said, “When did he die?”...I didn’t know. When they were interviewing Prince William [on the occasion of his engagement] I did not know that Princess Diana had died. I mean...all that stuff is gone, my childhood...most of it, is gone.

In contrast to the gregarious intensely energetic nature of mania, the experience of depression then includes sadness and diminished energy that leads one to isolate oneself from others. Participants in this study reported feelings of isolation, sadness, and unattained potential. Participants also reported they experienced changes in cognitive function.

Mixed

Some participants also reported experiencing mixed symptoms. That is, symptoms arise simultaneously from both the manic and depressed ends of the mood spectrum. A common view of bipolar disorder might be a person either experiences depression or mania episodes but mixed symptoms do occur. A person may experience the high energy and restless of mania and be weeping with despair. Cathy described her personal pattern of mixed symptoms that she believed would happen if she were to discontinue her medications:

If I stopped taking my pills right now, like in two days, I’d be in the hospital. Two days without my pills and I would be in the hospital. I would be a depressed manic. Because I would be crying and rocking in a
corner.....those would be the two main things...and not seeing. When I say that I mean you might be sitting there but I may not necessarily acknowledge or see you...you would be talking to me but I wouldn’t hear you. I just shut off the whole world.

Pregnancy

Pregnancy brings challenges for women diagnosed with bipolar disorder. The physiologic changes and psychological stresses that go with pregnancy exacerbate mood instability. More important, in this time of perhaps greatest need for medications, a woman finds herself unable to take them. Nearly all psychotropic medications including anti-depressants and mood stabilizers increase risk of abnormal fetal development during pregnancy (Yonkers, Wisner, and Stowe, 2004). Prescribing instructions for medications used to treat bipolar disorder including mood stabilizers, anti-depressants and anti-psychotics all state that these medications have been shown to cause fetal abnormalities in test animals or humans during all or portions of pregnancy.

Susan, who was two months pregnant at the time of the interview, described the day she learned she was pregnant. She had been living for some months in a committed relationship she valued and for which she had great hopes. She had been successfully managing her bipolar symptoms most of the time but the she discovered she was pregnant. Susan was quite animated in this section of the interview but became quite pensive and smiled slightly when she reported feeling happiness:

I went to the doctor’s and “you’re pregnant! You’re pregnant, congratulations!” And I was like, are you fuckin kidding me!! Are you serious? And she’s like, no ma’am; I don’t play around. And, like great! I thought he [the father] was going to leave but I should have known better.....we’ve been faithful to each other this whole 10 months! So that really feels good for both of us. There’s a lot more, what’s it called....happiness? [speech slowed here, unpressured, smiled]
I’m pregnant, just kind of “ughed.” I’m happy about a lot of things but...see, that’s it right there! I’m happy but there’s a lot of things that I’m stressed out about and I’m just trying to balance it all and it’s hard without medications!

Gina, eight months pregnant at the time of the interview spoke about her decision to become pregnant. She reported her discussion with her husband:

We dated and fell very much in love with one another and got married and um, then when we decided to have children we...I told him like this isn’t an easy, uncomplicated thing like a lot of people say, “oh, let’s have kids” so they stop taking birth control. Well, [laughs] that’s not how it works for me!! ‘Cause Depakote is dangerous to children, to fetuses, I had to stop taking my meds and I told him that likely everything will go really well until it doesn’t go well and all the wheels fall off the wagon....which actually has been what has happened. [She described episodes of recurrent depression that necessitated monitoring by family and loss of driving privileges.]

In summary, the first theme that emerged during data analysis is diagnosis brings understanding accompanied by irrevocable change. Diagnosis of bipolar disorder gives meaning to past behavior, thoughts, and feelings. Diagnosis is also the herald of a distinctly altered life path life. Thinking, feeling, and spiritual beliefs will never be the same. Life becomes more complicated. Even common milestones such as planning for and undergoing pregnancy take on added dimensions for persons with bipolar disorder as couples attempt, largely unguided by health professionals.

Theme Two: Finding Effective Treatment Is an Interminable Process

Participants’ stories revealed a second theme that that centered on the lengthy and painful struggle to obtain effective treatment with minimal distressing adverse effects.

For most participants, the initial encounter with health care providers occurred with hospitalization following a psychotic break. It was in hospital that the participants were
diagnosed, began establishing relationships with providers, and were started on medication.

Hospitalizations

The reasons for initial hospitalizations varied. Some participants, including Gina, were initially hospitalized for major depression. The bipolar disorder became evident as treatment progressed. As Gina explained:

Well, I was 15 when I had my first major depressive episode where I went way, way down. My biological father killed himself when I was 12. And um, a lot of that, I think, um ...because I had my mom and my sister, and I very much focused on their grieving process - I don't think I really started to do a lot of active grieving on my own until I was about 15, 16. And um, I was inpatient in XX Children's Hospital, for about a week and a half when I was 16. And um, what happened was, when I had the depressive episode, they put me on an antidepressant, which corrected the short term problem, but caused long term issues with my bipolar because it makes my ups and downs much worse.

Cathy also described how she was committed initially for involuntary treatment for something other than bipolar disorder. She was placed in a mental health hospital for psychosis after a change in medicines. She was treated and released but then she was soon re-hospitalized and diagnosed with bipolar disorder.

Um, the first hospitalization was medication related. Cause they had put me on some antidepressants for migraines and quickly took me off of them and I started ripping off my skin. So that time, they called it something, I don't even remember...no, it was medication induced psychosis I think is what they called but the second one, Dr. XX diagnosed me with bipolar because I literally was not there. [Spoke slowly, emphasizing each word.] I was basically....gone down to 100 pounds, couldn't eat, couldn't drink....couldn't sleep...basically just sat there and rocked.

Most participants found hospitalization frightening and dehumanizing. For example, Robert appeared quite agitated and angry as he described his first experience.
Um, I was in the hospital first as an inpatient. They had a psychiatrist come to my room. That's what they diagnosed me as, they shipped me to I guess you could call it a psych ward. Oh terrible!!! [Pressured speech] Terrible. I mean I don't understand why people have to go through that. Everything was bad. The food [chuckles]. The stay in the hospital. Um, the treatment of the doctors, of the psychiatrists. They treated you as like you're nothing, you're not worth anything, you are a nobody....we really don't care, we are doctors - we make six figures you make $15,000 a year...you know that type of thing. Yeah, yeah. It stays with me....probably will stay with me for the rest of my life.

The hospitalization related experience lingered after discharge for the participants. The ability to function effectively or meet role expectations was slow to return. Bailey reported:

....evaluating how I felt right after I got out of the hospital is hard because I was sooooo not ready to come out of the hospital [loud, emphatic, seemed frustrated] ...and I was still out of it. I was out of it for a good six to twelve months after I came out of the hospital.... Yeah, a year. When I say like recovering I mean like a year to maybe 18 months before I was able to go back to work, go back to school, feel like I could function everyday - it was hardcore...it was a long time!

Hospitalizations prior to diagnosis with bipolar disorder are often intended to treat other mental health conditions. Bipolar disorder tends to be diagnosed during hospitalization. The experience of being hospitalized can leave one emotionally drained and physically weakened and feeling devalued.

Relationships with Psychiatrists

Participant stories revealed tenuous and uncertain relationships at times with psychiatrists. Finding a psychiatrist whom one trusts and with whom one is comfortable can be seemingly effortless or sometimes a struggle. Bailey described her encounter.

Well my family doctor prescribed the Celexa. That first time when I was really depressed and I went to the doctor. I had lost like 15 pounds and wasn't sleeping at all. She said, "You need to see a psychiatrist." She
prescribed the Celexa and then transferred my file over to the psychiatrist. And I've been with him since then...so...we have a good relationship.

Other participants reported having difficulty building a relationship with their psychiatrist. Jackie reported her challenges.

Ah, I had a really bad psychiatrist. Well, I had a really good psychiatrist and she retired. And then I had a really bad psychiatrist. And um, I kind of need somebody that I can just call and change my medication and she, the last time before I was in the hospital, I called to get in. I called because I was going manic. And they always say if you mood changes call your doctor. So I did. Her receptionist told me she couldn’t get me in for 10 days. So I said, if anything comes up I need to see her sooner than that because I’m manic right now. Nobody called me back and ah, I ended up going to the hospital that time. Um, and I ended up getting drugged out and I’m lucky because my husband’s step-father is a psychologist and he referred me to this woman Dr. XX who’s awesome! She’s a psychiatrist [that] I really, really have a good relationship with.

Establishing a good relationship with a psychiatrist has not happened for other participants. Dora recounted her experience.

We sit and talk and the length of the visit is less than 15 minutes. And I had told her about SSRIs [Selective Serotonin Reuptake Inhibitors that hadn’t helped in the past and worsened her movement disorder symptoms] and she put me on one anyway. And I'm thinking, well she's a doctor, she should know these things. And I told her before. And told her what the results were going to be. And she said, let's try it anyway. So...the day I took it, it was just horrible. I said, I'm not, I'm not going to take it! And we are trying again and I said it didn't work the first time and well, let's try it again. So, I don't feel like I'm being listened to very often with her. I've been seeing her about a year and she still needs to look on the chart to see my name.

To summarize, participants reported mixed results from psychiatric intervention.

Some participants felt connected and engaged. Other participants perceived their psychiatrists to be distant and unwilling to listen to patients.
Relationships with Therapists

Psychotherapy, individual and group, often is conducted by providers other than psychiatrists. Care in a mental health hospital is provided by an interdisciplinary staff. Psychiatrists, as physicians, direct care and manage medications. Their contact with inpatients and outpatients tends to be brief and medication oriented. Nurses administer medications and monitor responses and manage the milieu or community on the inpatient unit. Therapists, clinical psychologists and other licensed therapists, provide psychotherapy according to particular theoretical frameworks or perspectives.

Participants’ stories demonstrated mixed thoughts and feelings about therapy. For example, Robert tersely responded to my question asking if he sees a psychiatrist:

Yes sir, and a mental therapist - a social worker. Um....I think they get more out of it than I do. I'll just leave it at that! [Voice was low in volume but pressured, looked angry.]

Bailey initially found some benefit to therapy at various stages of her illness but that benefit waned over time as her ability to function increased to the point it no longer was worth the time and money it required.

Um, I think at first, like when I was younger, it was very good to kind a talk about why I felt this way and to have somebody else, an outsider's perspective because I was so critical of myself. Oh Bailey, you twist your reality, you think everything sucks but really it doesn't! Um, so that was good. Um, it was harder when I was feeling manic if I was talking to someone because they....you don't want to hear the truth. [Therapist says] “That is a really aggressive response that you gave” when I was fighting with my parents or something and then I'd be like uh-uh [no] you're [therapist] supposed to be on my side, don't side with them. And then later on, like when I went to college, my parents would say like, “Why don't you continue with somebody, we'll pay,” but I was like, “I don't have like an hour during the day to take the bus from college over to your place and then talk for an hour and then go back!” It was just a pain. So that was kind of my experiences.
Three of the female participants stated their therapist’s gender made a difference.

Rita seemed to reflect the general tenor of the group when she stated:

Dr. XX is a female therapist. She’s the first female therapist I’ve ever had. Um, and she is a lot more confrontative [laughs] than they [prior male therapists] were, which is good, but she calls me on all of my BS which is interesting [laughs]. She doesn’t let me get away with much so....so I like her; I like her a great deal.

Participants generally agreed one must be actively engaged in the therapeutic process in order to achieve any benefit. Gina said:

Um, I found, and this is something I think is true for anyone, but um, unless you are actually going to commit to being there you are just wasting everyone’s time. You know, I got to be very good at telling the counselors my parents were sending me to, telling them exactly what they wanted to hear and just the right amount of things. My mother called it snowing. She said, "You just got really good at snowing people!" [laughs]. And you know that was part of the reason why my parents took me to a hospital. They just couldn’t...I was just lying constantly, I was telling people whatever they wanted to hear and continued to do whatever I felt like doing. And sneaking out of the house [impulsivity and disordered thinking potentially related to bipolar disorder] and....they had run out of options. And I was emotionally out of control.

Participants who actively engaged themselves in therapy and felt supported generally perceived a benefit. Dora’s comments are representative.

It helps. It's nice to have someone to talk to who knows what I'm talking about and can understand family...I have some family that have anxiety and depression so they understand the anxiety and depression part...um, the bipolar part is hard to explain to people who don't understand. And I've tried to explain it to my Mom and she says, Dora, I'm just not going to understand! So,...my therapist is in recovery for drugs I believe and he's been in recovery for years and years and years so he can understand some...the mental aspect and the recovery aspect of it. So, it's nice.

In summary, the participants generally found some benefit to psychotherapy provided they committed themselves to the process with a skilled therapist with whom they were comfortable. Participants reported a sense of being understood and finding
comfort and direction in that interaction. Therapy seemed to be more useful at various stressful points in life and less useful when participants perceived themselves to be functioning well. They did not uniformly find psychotherapy to be beneficial.

Relationships with Nurses

When beginning the interviews, I introduced myself as a nurse and professor of nursing. I did not specifically ask participants about their interactions with nurses. Nurses and nursing care were seldom mentioned by participants. Any comment about nurses came in the context of comments about providers in general. The most informative comment was from Gina. She said:

Um, and, in general - having been an inpatient in facilities before - the people who are in inpatient facilities can tend to be less sympathetic than people who are in outpatient facilities. That's been my experience. I don't know if that is necessarily true across the board. When I've been inpatient, um, you know, the nurses and stuff that you get - everybody's just doing their job and, yes, you can go and execute your job perfectly in a cardiac ward and that's exactly what's required of you but going and making sure that everyone's taking their pills but doing it without any sort of sensitivity to the real emotional pain that's going around you...it's...it's not as effective...I think - but that's just my personal opinion.

Nurses did not seem to make a strong impression in the lives of the participants as individual providers with distinct interventions. As this one excerpt shows, at least one participant perceived providers of inpatient services to be less caring than providers of outpatient services.

Medications

Diagnosis with bipolar disorder invariably leads to prescribed medication. Data analysis revealed three common areas of concern. All participants described a seemingly
interminable search to find effective medication regimens. All participants also reported how distressing side effects complicated this search. Some participants found themselves unable to obtain medications at various points.

All the participants reported being placed on multiple medications, sequentially or in combination. Participants described receiving anti-depressant, anti-psychotic, mood stabilizer, and anxiolytic medications depending on the types of symptoms they experienced. Bailey reported her experience:

Well my family doctor prescribed the Celexa. That first time when I was really depressed and I went to the doctor. I had lost like 15 pounds and wasn't sleeping at all. She said, "You need to see a psychiatrist", she prescribed the Celexa and then transferred my file over to the psychiatrist. And I've been with him since then...so...we have a good relationship. Um, other medicines that I've taken? Let's see, when I...we weren't...the Zoloft wasn't working so we went to the Effexor.....Well first we went to the Lexapro then the Zoloft and the lithium and that worked really well....but the lithium can be dangerous so we cut back on that. Then I started getting manic and decided I didn't need the Zoloft either so I cut back on that [laugh]. Um, then I went to the hospital. In the hospital I took... Zyprexa, um...I don't think I ever took Seroquel...I don't know, I was like on 9 medications when I came out of there [taking all of them at time of discharge].

Bailey’s description illustrates a healthcare phenomenon associated with mental health care. The medications potentially cause severe adverse effects and require careful monitoring by both provider and patient. Consequently, medication instruction to patients by nurses or pharmacists has become an important treatment component. Because of this ongoing effort to provide medication education, patients who are in the mental health system, in my clinical experience, often are very well informed about their past and present medication regimens.
Cathy described a similar medication experience in response to my question about medication history.

What's available! [Laughs] I mean, they've tried the old drugs, then new drugs. I mean I had a shopping bag, remember when Meijer used to have paper bags? Try filling up that bag three quarters of the way full with pills. That would be what I've tried. I would say I've gone through the gambit. I went to U of XX to make sure that....I went to the psych department at the U of XX because I was getting so frustrated because I was going through so many drugs. I'd be on it for two weeks and they'd take me off of one and then I'd be on another one and they'd take me off of it and....I literally had a bag full of drugs and finally between Dr. XX and I don't remember the doctor's name at the U of XX, and they sat down and talked there and came up with the regime I'm on now except for the Saphris. And finally, it was like OK, the combination is working. The combination is a combination of old and new school. I'm on Emsam. I'm on Topramax. I'm on Lithium and I'm on Geodon. And those are...and I'm on Saphris [she currently is taking all of these medications]. So...Lexapro, Zoloft ...you name it I've tried it.

Some participants report their symptoms are relatively well-controlled on their present regimens. Jackie stated, “I've got very good prescriptions right now, very good medications.” However, other participants report continued frequent medication changes in a search for improved outcomes. Robert said:

It works some but I do want to research other medications because I do hear voices now, constantly [voices, outside of psychotic episodes, are not generally part of the bipolar experience]. And I want to find what medication can stop the voices. And I'm not....Zyprexa helps some but I want to see what else is out there that, that, that maybe could help depress the voices. Actually, I hear them all day, all night [he was very guarded and would not disclose what the voices say during the interview] - even when I take the medication, before I take the medication and after I take it.

The lengthy search to find effective medications can be discouraging. Dora said:

I'm really upset that I'd been on so many medications and that they didn't work. Um, we ended up changing depression medications every 2 or 3 months just because they didn't work so um, just upset at how it turned out. Just frustrating. Um, medication wise I know it hasn't gotten much better. I don't really see a difference with medication. I mean. I don't
know how it would have been if I hadn't been on medication. How it would have progressed but I don't see any real good things coming out of the medication because I'm still depressed all of the time.

Dealing with Side Effects

Each participant reported experiencing distressing side effects that required changes in dosages or medications. These adverse effects included physical and emotional signs and symptoms. Robert related:

Side Effects - weight gain was one, a big one. But [laughs] I've lost all the weight. The weight was the one that I hated the most. Actually, most of the, most of the, most of the [sic] psychiatric medicines made me gain weight. Other than that - I'm sweating, lymph nodes...that could be from the weight gain...um....long pause, ah, ah, appetite goes with the weight gain, tardive dyskinesia [his phrase] a little bit.

Bailey’s experience was similar in part but had differences. She did not report tardive dyskinesia. It is important to note her difficulty sometimes in determining what was a side effect from medication, versus a disorder symptom, versus an unrelated phenomenon. She said:

Well, when I first started taking Celexa and Lexapro I had weight gain, I was hungry all the time. And then um, with lithium I kind of had tremors, not too bad, I was kind of lucky with that. Um, and urination at night. Right now I don't have any of that because I've taken it for so long. The stuff in XX [psychiatric inpatient facility], I was extremely constipated and I was starving all the time. I literally would have eaten my hand off if I could [laughs] I was so, so hungry. That was the Zyprexa, I think the average weight gain is 46 pounds a year or something [patients have been reported to gain 25% of their baseline body weight in a year, Zyprexa, 2011]. It's ridiculous! So, there's that. Ah, ....I was really...I can't remember....I think I was really starting to get panicky...I don't know. It was kind of hard to distinguish what was a side effect of the medication....This was right after I came out of the hospital. It was like, holy shit, what just happened?! Like coming down from all these things and I had big panic attacks after that. And so, that's when I took the Klonopin and the Ativan....,
Participants also described frequent emotional side effects. Generally, participants experienced a decreased ability to feel the full emotional range and exhibited blunted emotional expression. Bailey described it this way.

It's kind of like if you see a cat, a wet cat along the side of the road and you think, "Oh, that's so sad, that's so sad" but you don't FEEL SAD [her emphasis]....kind of like a disconnect between what you are thinking and what you're feeling.

Cathy had a similar experience. She noted finding herself unable to feel joy on happy occasions or normal sadness in other circumstances. Cathy described the need to be able to experience the full range of human emotion. She reported:

...if you think of all the emotions as A is your peak, B is your middle, and C is your down - my meds have been keeping me right at B—um, for this last 18 months. I don't have As, I don't have Cs - I have straight Bs. And they're trying to get it to where I have some As and Cs cause it's not right to live in just Bs. You have to have emotions. And I'm newly divorced um so they wanted to keep me there through the rocky part of that but now I need to go through the grieving process of losing a husband, losing my best friend....and that kind of stuff...

Access to Treatment

Several participants described financially insecure times in their lives when treatment was not available. Impoverished people experience unstable housing situations that can complicate access to treatment. Susan described an episode in her life.

We [she and her boyfriend] stayed with his brother a while in XX [small town] for a while and they got sick of us and so we had to get out of there. And, this time I wasn't on my medicine, so I was kind of intolerable, which I understand completely. I didn't have insurance. My Medicaid thing ended during the year and I didn't have a permanent address so I couldn't get all that stuff 'cause I was still on the move.

Participants described the hunt for effective medications as a continuous effort to achieve ever greater symptom management while diminishing adverse effects.
Participants reported feeling discouraged by the search, troubled by side effects, and hopeful for improved efficacy. Participants also reported difficulty feeling connected to providers. Psychiatrists were sometimes perceived by participants as helpful providers who prescribe effective medications but were seen at other times as disconnected and disinterested. Participants generally perceived therapy as being useful at times and not needed at other times. Hospitalizations were seen by participants as horrible experiences to be avoided but sometimes are needed. One participant in particular described inpatient providers as less caring than outpatient providers. On a cognitive level, participants grew to understand the imprecise trial and error approach to effective medical management but, affectively, experienced frustration and discouragement. Cognitive and affective characteristics emerged in this area but spirituality did not. In summary, the search for effective treatment seemed to be an interminable process.

Theme Three: Bipolar Disorder Is the Third Partner in Any Relationship

People who live with bipolar disorder report effects of the disorder on interpersonal relationships including relationships within the family of origin, among friends and acquaintances, and romantic partners. These areas are discussed below.

Family of Origin

Participants in this study also described events in their families of origin that they believed had contributed to their development of bipolar disorder. Participants also reported positive family histories of mood disorders. Two of the participants experienced the death of a parent during their adolescence. Both of them raised the subject of the
deaths when asked to describe the general circumstances around the time of diagnosis. I noted an affective response of distress. Dora reported:

I can't recall many [happy times at the time she began receiving mental health care]. Um, maybe before my dad died. So, 2001 when things were just stupid high school dramas and I wasn't an adult yet and things were just simple, um. I sort of had to be an adult after he died. And then it all just took a turn for the worst. And all....not a happy graduation because he wasn't there. Um, not a happy time going to college because he wasn't there. Um, I don't have many happy times. It was very sudden. It was a...well it was a second heart attack and it was in our old house and mom found him. But because she was screaming, I got out of bed and I didn't have my glasses on so I still can imagine a blurry picture of him, um but I'm glad I didn't have my glasses on! Because, just the blurry picture haunts me sometimes.

Gina described the events leading up to her first mental health hospitalization. A section of a quote that I used previously reminds the reader of her history:

Well, I was 15 when I had my first major depressive episode where I went way, way down. My biological father killed himself when I was 12. And um, a lot of that, I think, um...because I had my mom and my sister, and I very much focused on their grieving process - I don't think I really started to do a lot of active grieving on my own until I was about 15, 16.

Cathy experienced living with an alcoholic father and his subsequent death. She also later experienced being sexually victimized by her step-father. She reported:

I didn't like my childhood much. And it's very hard sometimes when my mom still clings to the memory of my step-dad and I couldn't really give a rat's ass what happened to him. In some ways I never had closure but that's OK cause he's gone anyways. But when she gets all, well your dad [mom referring to step-dad]...it just drives me nuts when she does that because that's not my dad. My dad's dead too but that's not my dad. My real father was an alcoholic and um from the time I was 9, the only time I could spend with him was if I went to the bars with him on Friday nights. So...30 years ago I used to sit at XX [a local tavern that is still open] with my father drinking orange juice playing pinball...it was rocky but...it was all I knew.
Cathy went on to describe how she came to hate her step-dad and was placed into foster care, noting connections to spiritual distress:

.... my step-dad could act so high and mighty in the church and be doing to me what he was doing...and...it just...kind of like...just shut it off [religious practice] for a while...I didn't believe it...he sexually abused me.

It is standard practice for mental health providers to ask about family history of mental illness when conducting a initial assessment. Having a positive biological family history of mental illness, particularly mood and anxiety disorders, also appeared to be a frequent thread in all but three participant narratives in the current investigation. Susan was adopted as an infant from an orphanage in Eastern Europe. She said she had no knowledge of the health history of any biological relatives but wished she knew their medical history in case it had any relevance to her own health and that of her baby. Robert’s father was not present during much of his youth and Robert never came to know his father before his father’s death from heart disease. As far as he knows, Robert says, his mother and siblings have no mental illness. Cathy reported her biological father’s alcoholism but her mother and brother, to her knowledge, have no mental health conditions. The remaining five participants all described blood-related relatives with mental illness, predominately mood disorders such as depression or bipolar disorder. Two examples follow. Bailey described her father:

My dad was diagnosed with bipolar disorder when he was like 18 or 19 and while he was in a manic phase he was in a terrible car accident and almost died. That's where the brain injury comes from. He does not take medications for bipolar and hasn't for years. Um, I don't think he considers himself bipolar but....it's out there.

Jackie described her parents and other relatives at several points during our interview:
I grew up with a mother who it turned out after I was diagnosed with bipolar 1, she was diagnosed with bipolar 2. So, I think I felt I was doing ok because I was comparing my behavior to my mother's...and was thinking that I'm not as bad as my mom so I'm not that nuts! Um my Dad has had chronic depression since the early 90s. He probably had it his whole life. He's not medicated right now my Mom is. I don't know if she's well medicated though she still gets a little nutty but....um, then I have a brother and sister who are younger than me. My brother has been hospitalized for depression....my Dad jokes that we need the family rate.

It was my grandfather drinking himself to death and in my dad's family there's been a couple of people [who committed suicide] but nobody's ever very specific about it. When I found out and was diagnosed everybody started talking about these people [laughter] who had these "issues" and my dad actually had an uncle who was married and had kids who one day just up and left and moved in with this woman on the Jersey shore and um his son was actually in medical school at the time and he went through where they learned all about the psychiatry he was taking those classes. And they were talking about bipolar disorder and he was like, "whoa, that's my dad!" So they actually went and got him. He went home with him, which worked out very well for him. His wife actually wound up taking him back and he ended up living his life - for the rest of his life, he was on lithium...it was a good life.

The participant stories indicated mood disorders, in general, and bipolar disorder, specifically, threaded through multiple generations and branches of most of the participants. These diagnoses sometimes helped other family members understand the behaviors, thoughts, and feelings of some participants. Other participants found the symptoms exhibited by family members to be sufficiently distressing to exacerbate their own symptoms.

Partner

The participants reported the symptoms associated with bipolar disorder affected their relationships with romantic partners. Some participants described how their bipolar
disorder symptoms created anxiety or fear, affective domain, in their partners during the early days of their relationships. Susan said:

And uh, the boyfriend that I’m with, he’s seen me when I haven’t had my medicine and he’s like, you’re crazy! It’s like a whole different side of me. It’s scary. See, right now, this is me when I’m just ‘alright’ and I’m just chillin’ whatever but if I get mad...it takes a lot to calm back down...... Like my boyfriend, he has a hard time dealing with it and I understand that, you know. I don’t expect him to fully understand or...cause it’s hard ...if it’s hard on me, I know it’s going to be hard on someone else to deal with it. So, when he sees me get all upset and he thinks it’s for no reason, well really—it’s like all the reasons in the world to me! That’s what’s hard. That’s what’s really hard. And I say, you don’t understand! But of course, they’re not going to.

Bailey recounted her new husband’s fears when they married a year prior to the time of the interview and the persisting impression her mania symptoms made on him. She reported:

I was manic when I got married. And it was very, very difficult for us because I was not me and I was really rude and I was not appropriate with lots of people and I hurt my husband, my John, a lot. He knew, I mean he knew I was taking medication and all that stuff but he'd never seen that before. And so, somebody who changed that dramatically is scary for anyone - especially when it is your wife! Um, so it causes huge stress on relationships, huge stress. .....luckily, it worked out ok and he was like....I remember him saying at one point in time that if this happens again, "I'm done - I can't go through that again" and I was like, "Well, me neither!" Things are fine...he gets more worried like if I don't sleep one night or......he's more like - if I go to the doctor, "What did the doctor say?", something like that where before that was something that I would take care of but he's more like that now....

At times, participants spoke of a reluctance to enter an intense enduring relationship. Robert, age 38, said:

I, honestly don't like committed relationships - that don't sound good for my disorder but I don't like to be tied down and I'm not really looking for a wife or to get married and have kids. Actually, I prefer not to have any kids - I don't want to put them through what I've been through and ......so......I don't want kids.
Dora also reported a long-standing preference, I noted a cognitive and affective domain connection, for short sequential relationships and her practice of ending them to avoid entanglements. She disclosed:

Yes. Um, got married and divorced very quickly. My relationships....in the past...before I got into AA and NA were um [long pause], from my standpoint, they were purely sexual because I don't like you enough for you to be around all the time. Um and it was to save myself because I didn't want anyone to get into my world, um....so relationships were always ended by me. And, they didn't get that close because I didn't let them get that close.

Some participants exhibited insight as part of a cognitive domain response. They anticipated the potential difficulties that could arise in a relationship and attempted to intervene. Gina described her efforts this way:

And when I met my husband and got some stability in that area of my life and um, and also our marital relationship - people are like, "we're just going to get married because we like each other"....well we [her emphasis] started premarital counseling when we started dating and talking to one another and learning how to communicate with one another and learning how to ....I mean we had to put a lot of work [her emphasis] into simply having a healthy relationship. And, I look at it as sort of a mixed blessing in that way but I feel my husband and I have the tools to have a relationship that lasts in a healthy way for the rest of our lives and there are some people who get married when they are very young or even at my age and don't have those tools but we've had to be very conscientious about them so when it gets tougher...when I'm not being rational or even he's not being rational because he's a recovering alcoholic.

For some, the partner is a primary source of caring and support. Jackie described her situation this way:

And um, my husband is just ....amazing. He's just a wonderful guy. He is the most supportive human being on the planet...of anything I've decided to do with my illness and other things. I mean... he's incredible. He's the one who set up the new psychiatrist for me after the one was not working and um, he just ....he's just so supportive. And he's educated himself and has taken on a lot with the kids especially when I was a zombie. And he's just so good.
Some participants described times when they were unable at times to successfully maintain relationships due, in part, to symptoms associated with bipolar disorder. Rita and her husband married 19 years prior to the time of the interview and had lived together before marriage. Rita stated:

Um, I tend to be more talkative, outgoing, and flirtatious and I have to really monitor that.... Well, I have a history of attracting really bad men into my life even though I'm married.... We um, our marriage....we've both been unfaithful. We've put it back together. I think we’ve forgiven each other. He doesn't really want to talk about it but he knows and I know and we just kind of move on from there. Um...so, we've had infidelity.

The above stories suggest a person’s bipolar disorder experience affects relationships with life partners. Some people with bipolar disorder make cognitive choices to avoid enduring relationships and their associated complications to reduce or prevent distress or sadness. Other people living with bipolar disorder decide to commit to another and approach the relationship from a day by day perspective, a cognitive decision made in hopes of achieving happiness. Other people decide to intentionally develop a plan to strengthen and support their relationship. The stories demonstrate having bipolar disorder adds additional stress to initiating and maintaining a committed relationship with a life partner. Participants demonstrated use of cognitive and affective domains in the relationship portion of their lives. One person experienced spiritual distress as a result of abuse by a parent.

Two of the seven female participants in this study were pregnant at the time of the data collection interview. Gina’s pregnancy was planned but Susan’s was unexpected. Two participants, Jackie and Rita, had experienced pregnancy and giving birth and were caring for their children. Neither Jackie nor Rita planned the pregnancies. Dora and
Bailey said they hoped to have children in the future. Cathy was unable to have children with her husband and regrets it. The stories revealed participants were chiefly concerned about the experience of pregnancy and monitoring their children for signs of mental illness. This section will consider each of those concerns.

Jackie reported:

Um, for a long time I would have stable times that would last for a while. But I think then my pregnancy kicked in to where I just went up and down.

Susan was just two months pregnant at the time of the interview. She expressed her anxiety as:

I’m pregnant just kind of “ughed”…I’m stressed out…there’s a lot on my mind, I’m happy about a lot of things, but…see, that’s it right there, I’m happy but there’s a lot of things that I’m stressed out about and I’m just trying to balance it all and it’s hard without medicine….I’m only about 2 months but still! And this is my first pregnancy experience so it scares me to death!

Gina was eight months pregnant at the time of the interview. She described her search, a cognitive domain response, for information about pregnancy and bipolar disorder.

I found that when I got pregnant and was going to be unmedicated for so long I started to try to do some research to see if there’s other people who had a similar experience or a other ways that people would cope with bipolar disorder and I was shocked that how little information there actually is. Not just for pregnant women who are bipolar who are unmedicated but, um, any information at all. Like, there’s just very few….there’s not even an online community even of people who are supporting one another with bipolar.

Gina further described the course of her pregnancy beginning with her concern about lack of medications:
‘Cause Depakote’s dangerous to children, to fetuses, I had to stop taking my meds and I told him [husband] that likely everything will go really well until it doesn't go really well and all the wheels fall off the wagon. Which actually has been what has happened.

Depression and disordered thinking symptoms that had been controlled with medications emerged in the last trimester of Gina’s pregnancy:

We did really well for trying and the first trimester and the second trimester and if the third trimester for even the first couple of months. But this last month has been very, very difficult and very emotionally trying and painful for both of us. And so, now, the reason I'm not driving is I've lost my driving privileges. I had a depressive episode and was...refused to come home.

Gina’s husband was concerned and urged her to allow some restrictions and to consider returning to her therapist.

And um, you know, my husband said we can't take these kinds of chances - I know you're feeling good right now but.....And so, now I'm seeing a counselor again, weekly and um…

At that point in fetal development, she was able to resume an anxiolytic medication meant to reduce anxiety:

I have Ativan which I can take in the evenings like a half of pill to help me calm. Because, when I get less sleep in the manic episodes, then the depressive episodes are much more difficult because I can't sleep.

Gina was able to take some medicine but believed she was still potentially capable of making poor or unsafe decisions:

I'm supervised most of the time. Either I'm with my mother and father-in-law or with my parents or my sister or my husband. So that's how we've been coping with it for...let's see....last week and the week before and for up until labor.

Aside from one female participant who had never been able to have children, nearly all other participants, including the sole male, believed their
current or potential progeny would likely have bipolar disorder. Susan, two months pregnant, stated:

And I know....I pretty much do expect my kid to have....bipolar or some kind of thing. I'm just going to watch out for signs. I know how to do that. I mean, ......I'm already thinking like I'm watching this kid close, like I don't want him to go through all that I did just to find out.

Jackie was watching her toddler preschool children now for signs of any disorder. She said:

Um, I'm very glad that I've been diagnosed and that I can look for signs in my children. It's very, very likely that they'll have some sort of psychiatric disorder but I also really want to be a role model for them on how to handle it and um how to just take some time if you are feeling bad and then if it persists to go seek help. And ultimately, I will be very supportive of them, whatever they do.

Rita has two children. She believes she has discerned signs of impending bipolar disorder in her 12-year-old daughter. She stated:

And I told my daughter, no, there's a very good chance you have this as well and you're going to have to learn with it and a maybe have medications for it because, dollars to donuts, you've inherited it. And I'm prepared for it, now I know what to look for. Now that I'm informed I can see in her... just I get it. I'm really trying to support her rather than trying to control her.

The stories suggest the belief that one’s children will inherit one’s bipolar disorder is common among people living with bipolar disorder. Participants expressed a shared view that parents must be vigilant in their efforts to monitor and discern emerging signs of mental illness in their children. Participants also felt empowered in the sense they believed they knew what to assess as a result of personal experience.
Friendships

The interviews showed that living with bipolar disorder has an impact on friendships. First, circumstances around diagnosis such as frequent or prolong hospitalization, desire to isolate oneself, or manic episodes may prevent formation and maintenance of social networks. Second, people with bipolar disorder sometimes experience stigmatization and may limit close relationships to those with trusted individuals. Third, managing one's bipolar symptoms requires effort and diverts energy from efforts to acquire and build friendships. Lastly, friends can be a source of gratification and support despite potential obstacles. Each of these observations is illustrated below.

Bailey first experienced mental illness in her early high school years. She reported,

Um, when I came out I was still....I was depressed. That was really hard - that was my freshman year of high school so I missed time. I was sick at first and then I missed 2 weeks while I was in there and I was like .....I took the whole...I think I took that whole semester....no, no, no - I went back to school. I did go back to school and it was just a lot of stress because...first of all there's the academic issue cause I wanted to do really well and I had to play catch up. And there was a social issue, I've been gone for this amount of time and where are all my friends? Now, we're all in high school and that's a change - what's going on? So, it was hard, it was hard...... And social also because I don't have any friends from high school...I have a few that I knew from before, just a few but when you are gone...when you leave for 3 months and refuse to answer anyone's phone calls cause you're so depressed - what are you supposed to do? Like people can only call you so many times or think so many things before they ....they kinda like, oh well, guess she's gone.

Participants described a fear of disclosing their bipolar disorder to people and limited close friendships to a very few trusted individuals. Jackie said, “I have very close
friends. I'm very careful about what I say to people because there is still this stigma about
mental illness."

Susan said she chose to not have many friendships.

I prefer not to actually because I just kind of get screwed over. And, I
mean I do have friends - people I hang out with but not like best friends.

Robert said he felt apprehensive around people. Robert also was diagnosed with
schizophrenia. He did not disclose the type but Robert exhibited some paranoid type
ideation during the interview. With regard to friendships, he reported:

I have some friends or acquaintances but I don't really have anybody that
is really close to me... at this point in time, right, right - until I get my
symptoms, my life under control. Once I become stable...if that will ever
happen. And at this time, um, socializing would be best and gathering
with people that want to be around you or talk to you - that would help but
at the same time it would hurt more because part of my symptoms are
people are out to get me for whatever reasons that I don't know why they
are out to get little old me. I mean I'm not on TV - I'm not a celebrity, I'm
not a politician. Why would they be after me? What have I done? What
have I done to them?

Gina shared a reluctance to be open with friends. She said, "I tend to be one of
those people who everyone feels like you're super-duper close because they tell you a lot
of stuff but when it comes down to it, they don't know that much about you [laughs]!"

Initiating and maintaining friendships requires energy. Some participants
reported feeling, an affective response, the need to use their available energy to manage
symptoms and a reluctance to assume any additional burdens from friends. Susan said:

And friends, like girlfriends - I have one, not really even one, we just kind
of hang out here and there and do whatever but I just kind of like it. I
don't want to be caught up in other people's drama. I have my own.

Gina values her small coterie of close friends but believes she needs to place some limits.
She reported:
Umm, I have...now...um, a very solid core of very close friends. And um, and this is something my husband and I were talking about the other night...you kind of get to this point in your life, and I think this happens with everybody, where "I'm sure you are very nice but I am not taking new friends right now." [laughs] It's like, "yeah you are really cool but um I have a lot of effort focused into the relationships I'm already in and I don't really have a lot of extra effort to give to you right now!"

Some participants reported feeling gratification, an affective response, with being connected to a few select friends. Often, best friends tended to be the significant other or family members. Other longstanding friendships with trusted individuals were also valued by participants. Cathy struggled much of her life to make friends. She has made one and reported:

And we just, XX and I just hit it off very well and for the first time in my life, I've been able to...I mean talk to her - I can call her in the middle of the day and say XX I'm really having a bad day and she will talk to me or I'm having a really good day. I mean it's the first person...I don't feel like I'm interrupting, if I am she will tell me or won't answer. It's the first time I've been able to do that give and take thing and not feel guilty about calling her. And, really just trying to understand each other...we have a lot of the same goals in life I guess. I mean she's married and she's got a 24 year old son but yet we just seem to really hit it off and I'm hoping that I don't....she's always worried that she's going to put too much on me and I'm always worried that I'm going to put too much on her so we talk about that...we actually talk about it and reassure each other that if you're going to be my friend, you know, this is what I envision our friendship as being is this...that type of stuff. So, it's been really nice.

Gina described her categories of friendships and their importance:

I would say that anymore, there's a very interesting strata of friends. There's the ones that you would go have a cup of coffee, go to a movie with, hang out sometime, and um there's um the ones that you call when you need help with changing a tire or you're painting your house. And then again, the closest friends that I have are my mother, my little sister, and my father and my brothers and my husband...my husband is my very, very best friend. And um, maybe four, I would say, people that when I get to the really bad spots.

Gina identified someone she called a soul mate:
I have other people that I can call and one of them has been my friend since I was 14. He and I have been buddies since high school. And um he was someone that I remained in contact with and that I stayed close with and he actually married a friend of mine from up here - that I set him up with on a date at my wedding [laughs]! But he and I have remained friends and through our marriages and through everything have stayed very, very close. And we always joke around that we're soul mates but it's in the friend way where like he will be in my life until the end of it. That's just sort of the way we look at it, just like my husband and my family but, um....I would say there are 3 or 4 very, very close friends outside of my family.

In summary, the stories reveal participants are reluctant to engage in large numbers of friendships. Sometimes, the circumstances surrounding diagnosis impede the expected development of social networks. Participants also disclosed a fear of being stigmatized, an affective response, by others and perceived a need to limit close interactions with a few trusted individuals. Participants also reported having finite amounts of energy with which to nurture friendships and decided, a cognitive response, to limit the size of their social circle. Participants did however report receiving pleasure and support from friendships.

Theme Four: Caring for Oneself Is as Important as Receiving Formal Treatment

Participants had given thought to what living with bipolar disorder is like and how the circumstances of having this disorder influence planning and living one’s life. Some of the participants in this study, based on the self-reported activities described in interviews, seemed to function well in activities of daily living. Other participants described life as happening to them, outside of their control and oppressive. Quotations are given below to illustrate participant reflections about living with bipolar disorder, the importance of caring for oneself, and hope for the future.
Reflections about Bipolar Disorder

Some of the participants expressed sadness and disappointment with life. Robert shared those thoughts and added a fatalistic perspective:

Ah, living with bipolar is stressful; it's hard it's hell honestly. I often think why me, why do I have to go through this...why was I the chosen one. Why was I the vessel....I don't know [he was raised in the Protestant Christian tradition, potentially a spiritual sense of predestination)! I would like to be on the other end actually, the other side of the screen but they chose me to be on this side and there's nothing I can do to break out of the prison that I'm in so...

Bailey viewed bipolar disorder as an endless task to manage symptoms with no guarantee of success. She said:

Um, it's kind of a weight, a heavy weight on my shoulders...not heavy but a weight...more of an annoyance, like a tapping on your head.....I'm always gonna have to know where my pill bottle is at...like shit, I have to go spend another $86 to get more pills and I have to go to a psychiatrist or go get my blood drawn, have to worry about this or that you know...um, and I have to worry, am I going to get depressed again. Like there are some days like .....maybe like, over a year ago....may it wasn't that long ago but I just woke up feeling off, kinda tired...no enthusiasm, oh my God, am I getting depressed again? When you feel like that....that's the scary part. You do the preventative things like Vitamin D and exercise but in the end if you're going to get really depressed, you are just going to get really depressed. And um....and you can't....that's what I think anyway...you can't interact or do something to stop it from happening. And that's scary - to be out of control like that!

Some participants described having bipolar disorder as one facet in a multi-faceted life. For example, Gina stated:

Um, right now, because I'm in a good mood today and in a good place...it's just sort of another part of who I am so it's not really that big of an issue. On a bad day, and again I think this is the self-involvement part of it - "it's not fair", the justice part of it, "it's just not fair!" I don't want to have to worry about all these things. I just want to have a baby [eight months pregnant at the time and frustrated with symptoms resulting from inability to take medication]. I just want to be married and have a baby and not have to be supervised for the entire last month of my pregnancy and not
have to put my husband through that and... and... check in with people all day. You know, it is just not fair... but [her emphasis] on the other side of it, of course, it could be a lot worse! And I am a fairly healthy person who can walk around and eat good food and enjoy the world around me and play in my garden and take my dogs for a walk and there are a lot of people who can't enjoy that.

Other participants described certain benefits in having bipolar disorder. Rita described herself as artistic and said the creative process helped her manage symptoms. She also reported selling her work was a source of supplemental income. She described bipolar as:

I think bipolar disorder, if you understand what bipolar disorder is.... I think of it as part of myself like having hypertrophic cardiomyopathy is an inherited disease. I've had it my whole life and when I knew about it, I could work with it. Bipolar to me is almost a wonderful gift in a weird way. The depression and sadness hurt but I feel and I like being able to feel and being artistic and doing the stuff I like to do... I really like... to me it's almost like a gift, a very dark gift. And I enjoy having it.

Some participants spoke of being treated differently because they had bipolar disorder. Cathy nearly shouted at this point in the interview when she advised others to be less judgmental:

Don't treat us like we have a plague! Realize that it's an illness like people who come in for pneumonia. You can't see it but it's still there. We might not have the same symptoms but....we don't like to be..... it's just like my mom still calls me fragile.... drives me actually nuts! I'm not fragile; just treat me like a normal person. I've just got a different disease process than somebody else. That would be my main thing. Don't hold it against me that I.... and don't mock me until you've walked in my shoes!

Participant reflections about bipolar disorder include a sense of a life-long need to monitor and manage symptoms, a certain feeling of the unfairness of being struck with bipolar disorder, being stigmatized by others. However, participants were also able to
identify other more satisfying aspects in their lives. Some participants even described benefits (see Rita above) to having bipolar disorder.

Self-care

All of the participants reported a belief that one must care for oneself and that self-care practices can be beneficial. Each participant identified strategies that relieve symptom frequency and intensity. These practices increase self-awareness, diminish stress and anxiety, and provide a sense of personal control in a life that diminishes powerlessness.

Participants stated that finding quiet moments to assess themselves and monitoring their moods is important. Robert said:

I found what's helpful for me, like I said, taking self-inventory, taking time - a quiet time, maybe to even be away from people just to take withal in yourself - I guess it could be a form of meditation but really not, just say - this is what I want to do now, this is what will help me stabilize myself to make myself healthier, this is what can take me um to getting the best the health possible in my life, I mean - maybe that could be reading a book for somebody, maybe that could be watching a movie.

Sometimes the monitoring is more formal and structured. Jackie, who was an English major in college, described the benefits she finds in journaling.

Yes, I journal everyday because that is very important for me to figure where I'm at. It's a big indicator and I do my mood chart - which I thought was really silly in the beginning but now I know it is really important.

Gina, the former actress, reported finding great comfort in words:

But as far as my journaling, I started journaling when my father died. So that is something I'd already been doing and writing constantly and poetry...constantly writing. I've always been a prolific writer. Um, that's something that does calm me because it channels me. Um, 'cause, when I'm writing, I can't do a number of other things...I can just focus on what I'm doing.
Several of the participants found engagement in art or music to be helpful. Susan described her use of music.

Or listen to music, music is a big thing [lots of energy]. I love music. They say things that....how I'm feeling....it's pretty amazing. All different kinds. It depends on what kind of mood I'm in actually. If I'm in the mood to go out and have a fun night, I'll listen to rap. I like Lil Wayne and the things he says. Like everyone listens to it just music but I listen to more than the music - I listen to the lyrics and what they're saying and put it together and it's like...wow [pressured, intense affect]! They're really saying something right here!

Dora described herself as a solitary type of person who spends a most of her time alone in her family’s home. She reported:

I paint, I listen to music. It seems to be something I can focus on that is not myself when I listen to music. I read so that I can get out of myself for a little while. I read fantasy. The Twilight Series [four volume vampire romance] especially. When I'm done with a series, I start again. I'm on the third book...again [laughs]... and the third movie just came out. So I have something to watch and then I'll start reading about it. It's kind of cool.

Participants stated finding time to be alone to rest or exercise was important. For example, Jackie said:

I just give myself some space. Like, I take some time to read a book or, if I need it, I take a nap...um, if the kids are napping in the afternoon. I just kind of give myself a break....eat some good food, and just take care of myself for a little while. I found....I just started running a couple of months ago and um I have a high that I can go to now. And uh, although sometimes I wonder if my runner's high is mania but then I come down in a couple of hours [laughter], "shoot"! I know that if I exercise, even if I just take a walk somewhere, I'll feel a lot better.

Setting aside one’s own distress and being helpful to others was described as an important method to ease distress and depression. Sometimes helping others meant aiding humans. Susan reported:

Even people I don’t know - I’d like to give support. Even, I mean, I’ve seen this homeless guy playing his guitar on the street. I gave him a bottle
of water and a hamburger. You know just little stuff like that. I mean, they’re happy and seeing them being happy makes me happy. So, that’s a plus. When me and my family would go on trips and I saw people in the corner, I’d say, “Mom, I don’t want to go eat until I give this guy something.” And she’s like—finally I would give him some water and a box of cereal that I have or Cheezits or whatever’s on me. You know? I care. Makes me feel so good. That little act of kindness helps me out. Makes me feel better.

Sometimes concentrating on others means one’s unborn child. Gina said she and her husband asked their physician to determine the gender of their unborn child as soon as possible because she felt the need to be able to think of the child as a unique person rather than an “it.” Gina recounted:

Yes [named her baby], XX, we talked about not finding out but actually the bipolar played a part in the finding out too because I wanted to give her a name and identity for myself so that when I had the really bad times this [cradles her abdomen]...this is a person with a name and not just something happening to my body. So, when I’m having a really bad moment I really try to focus on the fact that [potentially a cognitive strategy to relieve affective distress]...and I have a recording of her heartbeat...that helps me, I use it for relaxation.

For other participants, helping others can mean caring for a pet. Cathy lives alone in the house she purchased after her husband left her. She finds comfort in caring for her pets:

‘Cause they have unconditional, most of the time, love you regardless. My Solomon is 14 and I got the pets when we got divorced. And um...but...they're both dying. My cat's ill - he's 19. And my dog is 14 and he's a chocolate lab so he's old for a chocolate lab. They’re both not doing the best but.....they just...X took Solomon one weekend when I was on call and my house was so dead! I think a house without pets is so dead. And I didn't realize it until he was gone. But you know, it's like when I get home: Hi mom, how you doing? Let me just put my purse down and I'll let you out to go potty. Ok...it's like you take him out, he does his business and he brings you his bird [toy]. Want to play bird now - you throw it and he gets it.... they give me joy.

Gina recounted her connection with her dog. She stated:
That and a pet! This is something that I actually thought about recently
because, as I've been more and more depressed I have a border collie.
And I raised him from a tiny little puppy when I was 23 when I got him,
so I've had him for five years now. And this dog knows my mood
swings! He knows [her emphasis]... Like when I was single, he definitely
helped me through some really, really rocky times when I had no one else
in the house...I was by myself and isolated. And you see this other living
thing that you are responsible for and if you don't engage and get up and
get off the floor and feed him and take him outside and ...then ...he has no
one else to do it! And I feel like that has really....it may sound silly but I
feel [affective and cognitive, illustrates self-transcendence] like that has
been an incredibly helpful thing for me!

I asked each participant, “What role, if any, does religion or spirituality play in
you live?” Several participants felt spirituality, expressed as either in formal structured
organized religion or less formal casual practices, was helpful. Dora reported:

AA is a spiritual program not a religious program. So it always says in
any AA literature be god of your understanding so...my idea is there's a
god but dad's up there too. So sometimes I'll pray to him and sometimes
I'll pray to God. But, since starting AA I've gotten to be spiritual. I pray
multiple times a day, um. I try to have good values as best as I can. But I
finally found spirituality since starting the program. Sometimes, I will ask
for a sign and go outside. That's usually where I find the answers to my
signs is outside. Oddly enough, by noises... Birds, cats. There's one cat in
this neighborhood and the cat meowed three times outside my bedroom
window. And 45 minutes later I asked something and the same damn cat
was outside my window [laughs]. There's just one cat in this
neighborhood and it was outside my window. I had a hot air balloon go
by which was a sign because my ex used to rig hot air balloons so I saw
that as a yes to my sign.

Gina ascribes to a more formal practice. She described her family of origin’s
connection to organized religion:

Faith is something else that has played a large role in my coming to grips
with my bipolar. I ...grew up Christian. My father...my biological father
was a pastor, so was my grandfather and my great-grandfather and my
step-dad... [laughs]...so everybody's pastors!
Gina further described seeing service to others as a key component to living as one ought to live:

And a lot of my family life was focused around service because if you are not a pastor in my family, then you are a teacher. And so a lot of our natural tendencies just fall into how we serve other people. And I feel that aspect of my Christianity and that aspect of my faith of how do I serve others has really served me well in, you know, working with the kids at camp. All those kinds of things.

Gina found being of service to others helped her to avoid becoming self-absorbed:

Being led to do that um or having the natural ability or the natural inclination to do that because that's what was modeled for me as a child has been really, really helpful. I think...because...in my opinion, mental illness um specifically depression and um some of those kinds of things - the way it gets you screwed up is it makes your entire world just you! And it gets you so self-focused and so self-centered.

Bailey reported that her spiritual beliefs were challenged by the experiences associated with her mental illness and were now less formal and unconnected to organized religion but that a belief in a higher entity remained comforting:

When I was growing up I went to church every week [Church of the Brethren]. I did lots of fun things. We had youth groups and um retreats and stuff like that. So that was really good and then when I was really starting to get depressed around 14 and then getting manicky and that kind of stuff I was like I don't want to go to church. And that was also normal too - I was 14 and was like I want to sleep in on Sunday I don't want to go to church. Ah, I didn't really go to church for a while. When I was manic, I was extremely religious. I was real sure God was telling me [chuckles] to do lots of important things! Um, and now, I'm not religious. For a while, after being sick for that time, I was like uh-uh [no] there's no God! You know...good stuff would happen; this wouldn't happen to me and look at other people. I was negative about that. And now I'm more like um, I'm somewhat spiritual in the fact of...in the back of my head I do believe it's going to work out, somebody's going to make it all work out...something....someone, some entity - whatever - will make it all work out but I don't need to go and pray about it to make that happen.
In summary, the participants uniformly reported that one must take an active role in monitoring and managing one’s symptoms when diagnosed with bipolar disorder and these self-care practices can be effective. Self-care includes finding time to be alone and away from obligations, monitoring symptoms through self-inventory or journaling, healthy lifestyle practices, caring for others, and spirituality.

Hopes for the Future

Generally speaking participants in this study were hopeful about the future. However, the hopes and associated goals tended to be short-term. Susan stated:

The future? I’m nervous. I know there’s going to be obstacles; it’s just how I’m able to deal with it and kind a....look at the positive side. Things are going to be....things can get bad but it could always be worse too! As long as you know....I’ve got a roof over my head, I have food, I have a nice place to sleep,.....I’ve been to the point walking down the street homeless so I appreciate...I know how to appreciate things I have now because I didn’t have that before so.... just to get through this pregnancy without killing anybody [smiles]! And keep my head on straight. Priorities....!

Jackie also emphasized the near future:

Um, I feel pretty optimistic about it. I know it’s going to be hard for a while cause there’s the kids and stuff like that but um I’m pretty optimistic about it. I guess that’s all I can say about it...I feel pretty good. Some of the participants were hopeful but apprehensive. Rita said: You know, I’ve been out of work a long time. I go to the unemployment office and don’t find anything. I feel like I am as bright and creative as anyone else. I’m nervous about our financial situation. I’m looking for work. I hope I find work. I’m applying to a master’s program and I’m hoping I get into that. So, I’m hopeful and I’m also nervous. Gina also shared her mixed joys and anxieties about the future.

So, right now the future is looking really rosy and other than that, there’s definitely moments where I...where the anxiety comes in where I get afraid of losing my husband because I lost my father. And um, to watch my mom try to raise us by herself and that ...that ...those kinds of fears definitely strike to the very deepest part of me. ....and I'm also looking
forward to being able to take my medication again [laughs]! And, we may even find one that's more effective for me now that I'm not drinking or smoking.

Cathy focused her future hopes on managing her bipolar disorder,

I think my future's looking up. My goal is not to be in the hospital because I read an article that said if you've been in a mental institution once in your life you're probably going to end up there 10 times and I'm gonna try to prove them incorrect [laughs]. Cause, I don't...you know...I have a good job, I have a good manager, I have my own little house...you know....I don't know of anything that could, knock on wood [raps on the table], go wrong. I want to stay positive, you know, not....I just think that....I just think that for right now everything is going as best as I can expect it to go.

Robert wanted to find meaning and understanding. He said:

I said I don't really understand why I'm going through what I've been put into [potentially spiritual distress]. I really don't understand at all. And I probably....hopefully I can understand, somebody will make me understand but....I also understand that it is not fair and it is wrong. But I also understand there is nothing I can really do about it. But support - if I had the support of someone who could make me understand, then I might be in a better place. ......Like I said before, I was the type that was very educated, very intelligent, high IQ, very gifted - um, I don't know what the future holds for me. Right now I'm just taking it day by day, one step at a time. And I know there's always some options or some loopholes out there for me. Hopefully, I can play it right, the next time around - it will work out better for me.

Bailey was unequivocally hopeful:

Um, I'm very optimistic. I like, for the most part, I like my job and I like my classes a lot. And hoping that I will get into the nursing program someday. And um, I do like health care and ah I think I would make a good nurse um so, yeah.....

The future generally is hopeful but uncertain for participants in this study. With the exception of Bailey, the participants primarily saw the future in terms of days, weeks, or months rather than in years. The general sense seem to be participants believe one
should be attentive to immediate needs and problems and avoid making detailed plans for a distant uncertain future.

Summary

Four themes emerged during the analysis of the participants’ stories. Each of the four themes is considered below in relation to the cognitive, affective and spiritual domain framework used in this investigation.

**Diagnosis brings understanding accompanied by irrevocable change:** All of the participants identified diagnosis as being a life altering event. From a cognitive standpoint, participants gained an understanding that explained past, seemingly inexplicable thoughts and behaviors. From an affective perspective, participants described feeling defective and fearful of the future. Some participants experienced spiritual distress when they struggled with believing a loving God would permit their suffering and despair. Other of the participants found their spiritual beliefs and practices to be a comfort at the time of diagnosis.

**Finding effective treatment is an interminable process:** Each of the participants experienced a lengthy period of insufficiently controlled symptoms or distressing treatment side effects before an effective treatment. The affective domain seemed to be strongest with regard to treatment as participants reported feeling frustration and anger. Some of the participants reported making vigorous efforts to understand treatment regimen and report signs and symptoms to their providers.

**Bipolar disorder is the third partner in every relationship:** The impact of having bipolar disorder on relationships emerged in the experience of all participants.
The stresses of living with family members with mental illness including bipolar and other mood disorders were believed, both a cognitive and affective response, by some participants to be a factor in their own development of bipolar disorder. Some participants believed the loss of parents to death or abandonment played a role in their mental illness. All participants described their own bipolar disorder as affecting relationships with family, friends, and romantic partners. Some participants reported using cognitive choices and actions to strengthen or preserve relationships. Other participants reported feeling vulnerable and opted to limit contact with others to a select group of family and close friends.

**Caring for oneself is as important as receiving formal treatment:** All of the participants perceived some benefit to taking prescribed medications and some participants perceived psychotherapy as helpful. In addition, all participants developed individualized self-care practices that they believed to be as important in managing symptoms as the treatments recommended by formal health care providers. Some of the self-care techniques were cognitive-based such as learning as much as possible about bipolar disorder and management.

Other strategies were affectively oriented such as developing a small group of friends who could provide emotional support. Self-transcendent practices also emerged in this affective realm. Some participants found helping others (i.e. pets, or homeless strangers) provided them with a sense of gratification that eased their own distress.

Spiritual practices were important for a number of the participants. Although some participated in specific organized religious communities, others developed more
informal individualized spiritual beliefs and practices. The findings of this investigation and their implications are discussed in greater detail in Chapter Five.
CHAPTER 5

DISCUSSION

Overview

Chapter Five summarizes the main findings and examines the implications of this research for providers and persons living with bipolar disorder. The relevant implications are identified through considering the findings discussed in Chapter Four in relation to current clinical practice and literature. To interpret the findings, I also consulted the research journal notes I maintained throughout the investigation. The notes recorded decisions and modifications made during the research, observations made during the interviews, and other thoughts and impressions that would not have been evident from just reading interview transcripts.

The chapter begins with a discussion of the four themes that surfaced during analysis. Then the chapter continues with an examination of phenomena related to living with chronic illness. As noted in Chapter One, I anticipated the potential emergence of three specific phenomena: uncertainty, chronic sorrow, and self-transcendence. Self-transcendence was discovered in this investigation and is discussed below. Although uncertainty and chronic sorrow congruent with the definitions found in the research literature were not found in this research, potentially related phenomena did emerge and are considered in later paragraphs. Chapter Five concludes with a discussion of limitations of this research and recommendations for future investigations.

The four themes that emerged in the analysis of participant stories are:
1. Diagnosis brings understanding accompanied by irrevocable change,

2. Finding effective treatment is an interminable process,

3. Bipolar disorder is the third partner in every relationship, and

4. Caring for oneself is as important as receiving formal treatment.

The evidence supporting each of them is summarized in the paragraphs below.

Diagnosis Brings Understanding Accompanied by Irrevocable Change

Relief and Understanding

This investigation revealed evidence that some participants felt relief at receiving a diagnosis that named and explained previously inexplicable feelings and behavior. This affective finding does not appear in the prior literature. Affective responses described in previous literature included being shocked or distressed by the diagnosis and label (Behrman, 2005; Jönsson, Wijk, Skärsäter, Danielson, 2008), and feeling powerless (Strandmark, 2004), derailed (Sajatovic, Jenkins, Safavi, West, Cassidy, Meyer, & Clabrese, 2008), or in denial (Chafetz, 1996; Lundin, 1998).

Irrevocable Change

Participants also described feeling that being diagnosed with bipolar disorder changed their lives forever. Diagnosis sometimes altered relationships with family and friends, created new relationships with providers, demanded adoption of long-term treatment practices, and initial uncertainty and apprehension about the effectiveness of treatment. Participants described their feeling that there would be no return to their pre-diagnosis lives. Hayne (2003) referred to this as a “knowledge that knows.” She found this absolute knowing, this knowing that cannot be challenged or explained away, is what
most profoundly disturbs people with mental illness. This irrevocably changed life sometimes creates a need for control and safety (Thompson, Hunter, Murray, Ninci, Rolfs, and Pallikkathayil, 2008), leads to an understanding that loss and uncertainty threaten everyday order (Lundman & Jansson, 2007), and encourages development of a life-sustaining spirituality (Wilding, May, and Muir-Cochrane, 2005). All participants in the current investigation perceived diagnosis as a life altering event leading to a need to accept medical treatment and to develop self-care practices. However, only four of the participants valued strongly held spiritual beliefs and practices that they believed sustained them and aided in symptom management.

Some participants continued to wonder “Why me? Why do I have this disease?” Thompson et al. (2008), who studied what it is like to live with mental illness, stated that such questions reflect a lack of a belief system that explains and gives meaning to illness. Belief systems lie in the cognitive, affective, and spiritual domains. Thompson et al.’s statement may be an overgeneralization since some participants in the current study reported experiencing similar feelings at intervals despite fervent spiritual beliefs and engagement in religious practices.

Some of the participants in the current study related their feelings about having bipolar disorder as adults to how they felt about traumatic losses they experienced as children. Some related their feelings about being diagnosed with bipolar disorder to concerns that they might pass on the disorder to their children. These latter results differ from those of Thompson et al. (2008) who reported that none of the participants in their study that sought to understand what it is like to live with mental illness attributed the illness to genetic influences. In this present study, most participants, in contrast, believed
genetics played a direct role in the development of their own illnesses and would increase the likelihood their children would develop bipolar disorder. An example of this was when Susan stated her belief that her unborn infant would most likely develop bipolar or some other disorder and her intent to be vigilant in monitoring the child after birth.

Stigmatization

Participants in this study demonstrated a reluctance to disclose their bipolar diagnosis to more than just a few close friends and family members. Some participants stated they were uncertain of the reaction they would receive from others and feared rejection or another form of stigmatization. This is consistent with a study by Jönsson, Wijk, Skärsäter, and Danielson (2008) who reported that prejudices associated with mental illness led to increased feelings of being insecure in oneself. Lundin (1998) found it took more courage to disclose his bipolar disorder to friends than to strangers in an abnormal psychology class because of his feelings of shame and fear of stigma.

In his classic 1963 work, Goffman (1986, p. 4) identified three types of stigma. First, there are "abominations of the body" or various physical abnormalities. Secondly, there are "blemishes of character." Thirdly, there are the "tribal stigma of race, nation, and religion." Bipolar disorder doesn't clearly fall into any one of the three categories but is, as Goffman (1986) terms it "an undesired differentness from what we had anticipated."(p. 5). This differentness, being diagnosed with bipolar disorder, is sometimes seen by others or even the person with the disorder to define a person, to be that person’s identity (Sajatovic et al., 2008), a threat to self-esteem (Hayward, Wong, Bright, and Lam, 2002), and a source of shame, secrecy, and social isolation (Kranke,
Participants in the current study did mark the point of diagnosis as a turning point in their lives, but they did not necessarily convey affective responses that reflected feelings of stigmatization.

Some participants in this study described their fears of and experiences with stigmatization, but they also noted how they resisted letting themselves be defined by their disorder. Thus, it seems that they were applying cognitive strategies to cope with a threat from the affective domain. They also demonstrated application of affective strategies, such as listening to or playing music or keeping a daily journal in which to explore feelings.Thoits (2011) reported that successful resistance to stigmatization arises in two forms—both affective and cognitive. The first is challenging or confronting stigmatization through pushing back with an affective force of one’s own. The second strategy is to deflect or block stigmatization through, for example, cognitive-based efforts to maintain that one’s mental illness is only “one part of me and doesn’t define who I am” or to define one’s mental illness in terms that are less discrediting and stereotyped. As illustrated here, participants in this study employed both of these strategies in their relationships with other people.

Finding Effective Treatment is an Interminable Process

Although one participant in this study underwent electroconvulsive therapy (ECT) as part of her treatment regimen, the mainstays of treatment for all participants were medications and psychotherapy. Participants developed intense relationships with their medications, love-hate relationships full of hopes and frustrations. All of the participants
also participated in psychotherapy at various points in their lives. Experiences related to medication and therapy findings are each discussed in the following paragraphs.

Medications

Participants in this study demonstrated engagement in complicated relationships with their medications. Five of them were taking multiple medications at the time of the interview. One person took an antidepressant, a mood stabilizer, and an antipsychotic medication. Three people took a mood stabilizer and an antipsychotic medication. One person was taking two different mood stabilizers and three antipsychotic medications. One pregnant participant was not taking her usual mood stabilizer for the duration of her pregnancy and the other pregnant participant had been told to stop her mood stabilizer and antipsychotic medicines. One participant was on no psychiatric medications because they exacerbated her other medical conditions.

Seven of the participants, including the two pregnant women, perceived important benefits to regular medication use. The participants’ collective perceptions of medications included that they ease cycling moods, diminish feelings of depression, clear delusional thinking, and enhance one’s ability to function. The importance of medications is well described in the literature. For example, among people who had been previously hospitalized for bipolar disorder, those who adhered to daily medication as prescribed at least 75% of the time had lower risks of re-hospitalization (Hassan & Lage, 2009). Anderson-Darling, Olmstead, Lund, and Fairclough (2008) found people who adhered to their medications had fewer health problems, more effective coping with stress, a stronger belief in the success of their own efforts to manage symptoms, and higher life
contentment. Cole (2004), the successful Australian politician described earlier, reported medication enables him to effectively function in his public service career.

Each of the participants in this study, however, had resisted medication use at various points in his or her life because of adverse reactions or fear of injury to a fetus during pregnancy. They reported a variety of reasons for stopping medications including: stigma, poor relationship with the prescribing psychiatrist, feeling sedated and unable to function, weight gain, tardive dyskinesia, insomnia, or other adverse effects on the ways they felt or functioned. This reasoned (i.e., cognitive) approach to deciding not to take medications might shed light on what is reported as a tendency toward non-adherence to medication described in the literature. For example, Sanders (2008) and Jamison (1995) each described periods during which patients adjusted or discontinued medications on their own because of side effects or a persistent belief that symptoms could be managed through personal strength of will and determination. Each also described the subsequent decompensation leading to florid symptoms.

One participant in the current investigation chose to try going without medications due to a belief that she was strong enough to manage symptoms. However, she consulted with her physician and tapered from medications under his supervision. She subsequently experienced distressing symptoms that led her to resume medication. In addition, some participants reported modifying their own medication doses to reduce feeling sedated and to regain clarity of thought. Some of these participants modified their medications independently, but other people disclosed their attempts to their physicians. The findings of the current study may help providers and patients work together to differentiate which strategy applies in particular situations.
Finding the best combination of medications was challenging in itself to the participants in this study. All participants described frustration and periods of hopelessness and helplessness during a seemingly interminable search to find an effective and stable medication regimen that was accompanied by tolerable adverse effects. These findings agree with biographical accounts in the literature. For example, Hensley (2002) recounted her and her provider’s struggle to manage mood instability and psychosis without introducing new debilitating symptoms. In the current study, participants didn’t consistently feel a sense of partnership with their psychiatrists. One person, in particular, described feeling her provider prescribed medications for her bipolar disorder despite the participant’s objection that they were known to cause intolerable side effects in the past. Behrman (2005) stated 37 different medications were tried during the decade after his diagnosis before effective treatment was achieved without intolerable side effects.

Participants cognitively did perceive value in medications but they were unprepared for the length of time it took to find effective treatment unaccompanied by disabling side effects. Two participants believed they were still on a journey to find effective treatment. The trial and error approach, as they described it, led to feelings of helplessness and hopelessness. The literature also reflects the intermittent belief by some participants that symptoms could be managed without medications.

Therapy

All of the participants in this study had been in therapy at some point in their lives. Their therapists had primarily been clinical psychologists, although one participant received therapy from a licensed counselor arranged by her parole officer. Three of the
participants in this study were regularly participating in individual therapy at the time of the interview. One other person attended several group therapy meetings each week. Three participants had been in therapy but no longer felt it was needed at the time of the interview. One individual had just been told she needed to resume therapy.

Participant views of the usefulness of therapy were mixed. Participants evaluated therapy, in part, through a cognitive domain by considering effectiveness versus cost and convenience. Two perceived it as a waste of time. The rest believed therapy to be needed and effective during times of increased stress when managing symptoms, relationships, and life circumstances might be more of a challenge.

Further emphasizing the importance of affection connections, one participant was careful to point out therapy was only helpful if the participant was fully engaged with the therapist. This observation explicitly identified a prerequisite need for a therapeutic relationship connection between patient and provider that acknowledged mutual participation and effort to achieve commonly held goals. One participant in this study found that connection with her first therapist, but all the others spoke of meeting with several before feeling valued and understood, characteristics that lie in the affective domain. This is consistent with the work of Hayne and Yonge (1997) who described the “therapist connection” as a critical component that can bridge a path leading to healing and maintaining health. Mansell et al. (2010) and Chafetz (1996) reported a trusting relationship with one’s therapist enhances medication compliance.

Talseth, Lindseth, Jacobsson, and Norberg (1999) contrasted providers who either confirm or fail to confirm patient basic needs. Confirming includes such characteristics as having time for the patient, accepting feelings as expressed by the patient, and
communicating hope to the patient. Lack of confirming is demonstrated by not seeing the patient, not having time for the patient, listening to patients with prejudice, not being open to the patient and instilling feelings of hopelessness. Some participants in the current study experienced this lack of confirming. For example, Jackie recognized she was hypomanic and progressing toward mania. She called her physician’s office as she had been previously instructed, but she reported being told she could not be seen for 10 days. She ended up being hospitalized prior to her appointment.

Mansell, Powell, Pedley, Thomas, and Jones (2010) described openness, support, and feedback from others as being important factors in recovery from bipolar disorder. The connection is not always achieved, however, and people may feel unsupported and dismissed. An example of this is the woman described by Hayne (2003) who quit talking about her symptoms when her psychiatrist warned her that if she talked about hearing voices she would risk being “locked up.” In the current investigation, Dora reported feelings of being devalued and dehumanized when her psychiatrist of one year was unable to recall Dora’s name without looking at the chart label. Therapy was perceived by some participants in this study as an important treatment modality during periods of stress or as a source of ongoing support and guidance. Participants stated they needed to feel connected to a therapist in order for the intervention to be effective. These findings are congruent with the literature.

Bipolar Disorder is the Third Partner in Every Relationship

The thoughts, feelings, and behavior of people diagnosed with bipolar disorder can impact relationships with friends, employers, and romantic partners. One of the
findings of this study is not reported previous literature. Six of eight participants
described friendships as important sources of support and comfort but reported feeling a
need to limit the numbers of close friends. The numbers of close friendships needed to
be restricted to preserve energy to manage one’s own symptoms and to avoid taking on
the burdens of others. These participants indicated a need to almost isolate or insulate
themselves from close relationships with anyone else other than selected family members
or a very few selected friends. The literature, as described in an earlier discussion,
reports self-isolating to avoid stigma or as a result of insecurity but not to limit the
stresses that provoke symptoms or to maintain the energy needed to cope with symptoms.

All participants in this study also described feeling out of control at times because
of their illness, acting impulsively, and later regretting some behaviors. The participants
stated they felt a need to explain their actions and to attempt to repair the damage they
inflicted on relationships. Three participants related the impact of their bipolar symptoms
on their relationships with romantic partners. Another participant believed her symptoms
provoked her spouse into filing for divorce. This finding of damaged relationships
requiring repair is not described in the academic literature, but it appears in various
autobiographical accounts of living with bipolar disorder (Jamison, 1995; Behrman,
2005; Sanders, 2008).

Four of the participants, which included all of the participants who were in a
committed relationship, identified their spouse or partner as being their chief support
person despite occasional tumultuous periods following manic episodes. They each
described times when their feelings, behaviors, and sometimes delusions stressed their
relationships but, for these participants, the relationships endured and often strengthened.
Delmas, Proudfoot, Parker, and Manicavasagar (2011) and Hensley (2002) also found committed partners to be important sources of support in day-to-day coping with bipolar disorder symptom monitoring and management.

Six participants in this study stated that bipolar symptoms affected relationships with employers. Sometimes symptoms caused employers to terminate the work relationship, but at other times, impulsivity and frustration intolerance on the part of some participants led them to abruptly quit employment positions without considering the consequences. This is consistent with other reports in the literature. For example, Laxman, Lovibond, and Hassan (2008) found bipolar related symptoms can have a significant, negative effect on employment relationships and function which can lead to lost productivity costs for employers and increased unemployment rates for people with bipolar disorder.

One unexpected finding in this study was a common thread of parental loss throughout most of the participant stories. Susan had been placed for adoption as an infant and adopted into an all female household that was also fractious. Robert’s father had abandoned the family. Gina’s father committed suicide during her early teenage years. Cathy reported her biological father died of alcoholism during her teen years. Her step-father sexually abused her, leading to her placement in a foster home. Dora’s father died in their home from a heart attack during her high school years. Bailey’s father survived an auto accident, but remained impaired due to a head injury. Each of these participants lost the experience of potentially important relationships. Each person described pain and loss associated with these circumstances.
Some prior research has linked parental suicide with bipolar disorder in the children who remain. Tsuchiya, Agerbo, and Mortensen (2005) reported an association with parental suicide and development of bipolar disorder. The link with maternal suicide was strongest. Persons with mothers who committed suicide before age 10 were seven times more likely to develop bipolar disorder. Death or losses of a parent from other causes were not associated with bipolar disorder development in children. Wilcox, Kuramoto, Lichtenstein, Långström, Brent, and Runeson (2010) confirmed these findings. Tyrka, Wier, Price, Ross, and Carpenter (2008) found parental death from any cause and perhaps parental desertion were related to development of mood (including bipolar disorder) and anxiety disorders by their children.

In a summary of the discussion concerning relationships, it is notable that participants said that symptoms of their bipolar disorder did affect relationships. These relationships included those with employers as well as family. There are gaps in the literature but prior investigations (e.g., Laxman et al., 2008) also indicated the negative impact of bipolar symptoms on can have on employment. As noted in this section, prior literature also is consistent with this study’s finding of spouses being important sources of support and comfort. Participants’ stories in this study also indicated a need to limit numbers of intense friendships to preserve energy and to avoid taking on the burdens of others. Participants also reported a need to repair relationships after manic episodes. Finally, six of the eight participants reported the absence or loss of paternal relationships as children and described the impact that this had upon them. The literature indicated that in the case of suicide, this may have an association with the development of bipolar
disorder. It did not support causal connections for other types of parental death. Perhaps the common factor is a genetic link.

Caring for Oneself Is as Important as Receiving Formal Treatment

Caring for oneself involves cognitive, affective, and spiritual strategies. One participant in this study saw his life with bipolar disorder as a mystery. Acceptance is a cognitive activity. Robert plaintively asked during the interview, “Why was I chosen for this?” All of the other participants to one degree or another had come to accept bipolar disorder as part of their being. Some participants, Gina and Rita in particular, identified advantages to having bipolar disorder. Rita referred to her bipolar condition as the “dark gift” that brings creativity and energy along with distress. This acceptance, a cognitive response, has been found to be an important initial step in caring for oneself (Jönsson, et al., 2008; Delmas, Proudfoot, Parker, and Manicavasagar, 2011).

Participants’ stories indicated that people with bipolar disorder may begin to identify and cultivate ways of caring for and nurturing themselves after accepting the disorder as permanent. Sometimes the approaches seemed simple and uncomplicated. For example, Susan said she likes to do things that make her feel pretty, an affective response, when she was sad or frustrated. Jackie said that finding time to be alone and rest was important to her. Consistent with these examples, Borg and Davidson (2008) found “just doing it” and “being good to yourself” are effective approaches employed by people in recovery from mental illness episodes.

Participant stories in the current research clearly indicated that people with bipolar want to maintain a sense of being valued. For example, Cathy said, “Don’t treat
us as if we have the plague!” and “Don’t act like I’m fragile; I’m not!”. Some participants described feeling useful and valued by performing well at their jobs and other people reported experiencing positive affective responses by doing well at school or accomplishing daily tasks for themselves and family members. Thompson et al. (2008) reported people with mental illness struggle with feeling misunderstood and invisible in the world and struggle to repair injured self-esteem. The participants in the current study appeared to have found some affective strategies to counter such negative feelings by engaging in activities that made them feel good about themselves.

Participants also used cognitive efforts to cope with negative feelings. Six of the participants reported searching for information about bipolar disorder. Their effort to gain control over their circumstances is also reflected in related themes in prior literature: people have a need to gain control (Thompson et al., 2008), staying well means people have to be mindful of their illness and create a stay-well plan (Russell & Browne, 2005), people with bipolar disorder need to monitor and moderate emotions (Wilson & Crowe, 2009), and individuals with bipolar disorder avoid activities that lead to states of activation and promote lifestyle changes that enhance stability and function (Mansell, Powell, Pedley, Thomas, & Jones, 2010).

Spiritual practices were employed by five of the participants in this study. To some people, Gina and Jackie for example, spirituality meant belonging to formal Christian denominations and adherence to daily religious practices. Others, Rita for example, described an eclectic set of beliefs and values derived from life experience and multiple religious influences as being helpful in managing symptoms. One person looked for signs in the natural world to indicate a Creator’s will regarding her life events. One
other participant described herself as searching for a formal religious group with values that matched her own. The evidence of varied use of spirituality among these participants is consistent with previous observations that spirituality is unique to each person and supports people in coping with mental illness (Wilding, May, & Muir-Cochrane, 2005). Faith in God can be a frequently mentioned coping mechanism (Wilson & Crowe, 2009).

Participants in the current investigation also seemed to focus coping efforts to address day-to-day needs and challenges. When asked to share their thoughts about the future, only one participant identified long-term hopes and plans. I defined long-term in this context as being more than a year. Susan said, “I just want to get through this pregnancy without killing anyone.” Others, Rita and Dora for example, thought of the future in terms of signing up for a class or applying for a new job. Some participants perceived the future to be the next scheduled appointment with the psychiatrist to have medications adjusted. This existential present-time orientation for people with mental illness has been reported previously. For example, other researchers have reported a focus on finding ways to make daily life easier (Borg & Davidson, 2008) and being mindful and vigilant (Russell & Browne, 2005)

Self-care for the participants in this study appeared to mean using several strategies. Self-care means learning about the illness and medical treatment (cognitive), feeling valued and good about one’s self, and maintaining or development of spiritual practices. Participants also indicated a focus on daily monitoring and management of symptoms and less on planning for a distant future.
Phenomena Commonly Associated with Chronic Disease

As noted in Chapter One, I anticipated the emergence of three phenomena in the current investigation that had been reported as associated with chronic illness, primarily chronic medical conditions such as diabetes or slowly progressive disorders such as multiple sclerosis. The three phenomena are uncertainty, chronic sorrow, and self-transcendence.

Uncertainty

Uncertainty was defined in Chapter Two as “a cognitive state resulting from insufficient cues with which to form a cognitive schema, or meaning of a situation or event” (Bailey, Wallace, & Mishel, 2005, p. 735). In conducting this study, I wondered if people diagnosed with bipolar disorder would talk about experiencing uncertainty and whether it might any impact on their daily lives. As the results described in Chapter Four suggested, participants’ descriptions of their experience illustrated, for the most part, an expected cyclical pattern of relative wellness interspersed with episodes of mania or depression. Those stories demonstrate that the life course of bipolar disorder is predictable to a degree, but periods of uncertainty exist.

Uncertainty accompanied by hopelessness and frustration were feelings experienced by most of the participants when treatment first began. As discussed previously, participant responses to medication were often unpredictable and disappointing. Medication-related uncertainty, however, abated with time and finding medications that were effective. Uncertainty was also experienced by the two pregnant participants, but aside from the added distress of not being able to take bipolar
medications, it would be hard for me to say whether their uncertainty substantially differed from that experienced by any first-time mother. The uncertainty model described in the literature received only mild support from the results of this study.

Chronic Sorrow

Lindgren’s (1992) analysis of chronic sorrow was discussed in Chapter Two. Through her analysis, Lindgren identified four clinical attributes of chronic sorrow: (1) perception of sorrow or sadness over time without a predictable end; (2) sadness is cyclical and recurrent; (3) internal or external triggers bring to the person’s losses to mind; and (4) sadness is progressive and can intensify in the years following the initial loss. Although most of the literature reported in Chapter Two described chronic sorrow as being more commonly experienced by caregivers of a person with chronic disease rather than by people diagnosed with a disease, I wondered if people diagnosed with bipolar disorder would experience chronic sorrow.

The results showed all of the participants reported moments of sadness related to life events and some experienced clinical depressions. Robert appeared to be the sole participant, however, who was experiencing chronic sorrow. He described intermittent sadness since the onset of his mental illness. He often referred to the loss of the person he might have been and said his sadness was more intense at the time of the interview than in the early days after diagnosis. Robert also appeared to be experiencing spiritual distress when he sought meaning for his distress and an explanation for why he was “chosen” to have bipolar disorder.
Dora described feelings akin to chronic sorrow, but her sadness was cyclical and intermittent. It appeared to be more of a response to immediate losses (e.g. rupture of a relationship with her boyfriend) rather than sadness triggered by a new reminder of a previous loss. In contrast, the other six participants appeared hopeful and accepting more than grieving losses associated with bipolar disorder. Chronic sorrow was not commonly experienced by participants in this research.

Self-transcendence

Self-transcendence was defined in Chapter Two as “the ability to look beyond self and present difficulties, to extend concern to others, and to find personal meaning and wholeness in the context of changing life events” (Acton & Wright, 2000, p. 144). As a psychiatric nurse, I found myself mentally assessing the participants during the interview. I noted in my journal and field notes at the time of the interviews that the participants who were the most animated, hopeful, and happy seemed to be the participants who were engaged in activities with others. Contrasting with this pattern, Robert, who was the only one who appeared to be experiencing chronic sorrow, reported living a fairly solitary life isolated from people other than his mother, brother, and mental health providers. Dora, who also reported feeling more periods of sorrow, spent her days in an empty home. She attended group therapy several days a week but her only other reported social interactions were bowling with other group therapy members and watching TV occasionally in the evening with her family. Her affect during the interview was predominately subdued and sad.
On the other hand, Gina, Susan, Cathy, Jackie, Bailey, and Rita to some extent all engaged in self-transcendent activities that they reported as helpful. Susan said doing things for others such as giving homeless people food made her feel better. Gina described being of service to others as one of her most important coping mechanisms. Cathy called her elderly and frail pets her children and felt better when she attended to their needs. Bailey worked as a certified nursing assistant in an extended care facility. She reported meeting her residents needs improved how she felt. Her goal was to become a registered nurse. Rita reported some of the times she felt the best were those times when she as a group home staff member cared for developmentally disabled people. These participants indicated that forgetting their own difficulties for a time and caring for others helped them maintain periods of mood stability and happiness. This is consistent with prior literature indicating that self-transcendence maintains and improves health status (Upchurch, 1999), aids coping (Lindsey, 1996), and decreases depression (Ellerman & Reed, 2001).

All of these self-transcendent participants described themselves as spiritual. Gina and Jackie were fervent church members who actively participated in religious activities. Susan said she believed in good, evil, and karma. She said everything happens for a reason. Although, prayer or formal religion was not a part of Bailey’s life, she said she knew that there was a higher power and “things would work out.” Cathy and Rita described themselves as believers in God and searchers for a comfortable style of religious practice. Spiritual beliefs and self-transcendent practices appear to be used as methods of coping for some people living with bipolar disorder.
Implications for Clinical Practice

Findings from this study have implications for mental health care providers from every discipline. Most importantly, participants uniformly reported feeling a need to be valued rather than dehumanized in their therapeutic relationships. They contrasted this need with practices that they had experienced including brief medication checks with psychiatrists and perceived impersonal coldness of staff at inpatient mental health treatment sites. The findings from this study, therefore, point to a need for mental health care providers to be more attentive to establishing and maintaining the therapeutic relationships that would confirm to persons with bipolar disorder that they are seen as persons rather than as cases of a particular disease.

The two pregnant women in this study both stated they were told they couldn’t take bipolar medication during pregnancy, but they were not given guidance by their providers about non-pharmacological symptom management. Each participant perceived being essentially abandoned for the duration of the pregnancy by their physicians.

Pregnancy among women diagnosed with bipolar disorder is not rare. Mental healthcare providers should develop and instruct evidenced-based standards of care that include non-pharmacological interventions. Providers also ought to differentiate between adaptive and maladaptive cognitive reasons for ceasing to take medication, because there can be rational reasons for this perceived “non-compliance” in addition to irrational ones.

Providers need to understand that people living with bipolar disorder develop self-care practices and other coping strategies that could formally be accepted as complementary to medical treatment plans. These include creative practices such as
artistic and musical activities, reflective journaling to process emotions and build self-awareness, pet therapy, and nurturance of self-transcendent activities.

Strengths and Limitations

Like all investigations, this one had both strengths and limitations. Among the strengths, participants in this study demonstrated diversity in age (ranging from 19 to 43 years), but it was a limitation that all but one were female and white. The small size of the study (eight participants) was also a limitation. Although the participants in this study provided similar narratives about some common experiences, a larger number of participants would have made it easier to know when saturation had been reached. One participant was also diagnosed with schizophrenia, which may have introduced meaning units unrelated to living with bipolar disorder.

Challenges related to qualitative research with a small number of participants included the need to protect participants' privacy while asking them to tell their personal stories. This involved creating pseudonyms for the participants that originally helped me recall each individual, but may have increased risk of identification. I needed to change some of the names twice when it became evident that the names I selected could potentially have caused some confusion during analysis without greater vigilance. Another issue is that five of the interviews were conducted in a conference room with windows, and participants may have felt vulnerable displaying emotions so that may have affected some of the responses as well.

Perhaps the most important strength was the alignment of the qualitative approaches used to gather and analyze the data with the purpose of the study. Qualitative
research has clear advantages for exploring deeper meanings, such as the experience of living with bipolar disorder, which was the purpose of this investigation. The results indeed in terms of the insights shared by the participants are richer than likely would those that would have come from using a different research design and method. The three-step reading approach to data analysis also worked well for this purpose.

Suggestions for Future Research

Few studies have been conducted among the population of people with bipolar disorder. More investigations need to be carried out with larger numbers of more diverse participants to broaden the understanding of living with bipolar disorder. Research that follows up on childhood losses is needed, as this was a theme in the current investigation. Perhaps earlier intervention following parental death, for example, would mediate subsequent development of chronic mental illness. Additional research needs to examine the relationship people with bipolar disorder establish with their medications and prescribers. Finally, distinctions between cognitive, affective, and spiritual domains are imprecise and perhaps artificial. Further research needs to examine their boundaries and interrelationships.

Conclusions

This investigation revealed important findings that are not described in previous literature. The sudden understanding of prior unexplained thoughts, feelings, and behaviors gained at diagnosis permits people with bipolar to reframe past experience. For example, children who may have come to think of themselves as bad or disobedient for behaviors that later led, sometimes after many years, to a diagnosis of bipolar disorder
may, after diagnosis, be able to acknowledge that illness rather than moral weakness explained those behaviors.

Secondly, the participants in this study reported feelings of being defective after diagnosis. For some participants, those feelings persisted. Mental health providers could help people with bipolar disorder who may be experiencing similar feeling to acknowledge and process them.

Thirdly, it is important to note that some people with bipolar disorder have felt devalued and dehumanized by some mental health providers as well as the general public. Providers could examine their own approach and help advocate against stereotypes in the public forum.

Lastly, this investigation revealed that people with bipolar disorder experience happiness and personal accomplishment. Life, for them, is not just a series of manic and depressive episodes punctuated by hospitalizations. Most of the participants in this study found joy, purpose, and fulfillment in the cognitive, affective, and spiritual domains of their lives.
REFERENCES


Appendix A

Text of Participant Recruitment Newspaper Advertisement
Seeking adults, 18 years old or older who have had a clinical diagnosis of bipolar disorder for at least one year, to participate in a research interview (lasting up to 2 hours) about what it’s like to live with this condition. You may be invited to participate in a second interview. If you believe you meet the criteria and would like more information, call (517)-599-4169 or email richard.p.freedberg@wmich.edu
Appendix B

Invitation to be Study Participant
Invitation to Participate in a Study on

“The Experience of Living with Bipolar Disorder”

Doctoral Student Investigator: Richard P. Freedberg SFO, MSN, MPA, RN

Faculty Advisor: Nickola W. Nelson, Ph.D., CCC-SLP

Ph.D. program in Interdisciplinary Health Sciences

You are invited to participate in a research project on The Experience of Living with Bipolar Disorder. Richard Freedberg is conducting this research. The results will help to fulfill dissertation requirements for the PhD in Interdisciplinary Health Sciences.

What are we trying to find out in this study?

This study is designed to broaden the understanding among nurses, physicians, and other health care providers of what it is like to live with bipolar disorder.

Who can participate in this study?

- Persons diagnosed with bipolar disorder for at least 1 year
- Must be 18 years or older
- Must speak fluent English
- Must be able to give clear focused answers to interview questions
- Must be willing to participate in an interview lasting up to 2 hours and a second interview may be requested (participants are able to decline).

Where will this study take place?
A meeting room at the Lansing Community College Library or other mutually agreed location.

**What is the time commitment for participating in this study?**

The total time commitment is estimated as 1 to 2 hours plus any time involved in traveling to and from the interview site. A single interview is planned, but a second meeting may be requested if needed to clarify information from the first interview.

**What will you be asked to do if you choose to participate in this study?**

- Complete a short demographic questionnaire
- Give your permission for the interview to be audio recorded and for the interviewer to take some notes (Audio recordings and notes will be kept in a secure location and will be destroyed after the interviews have been transcribed and reports on the research have been completed.)
- Respond to questions asking for information such as age, employment status, race/ethnicity, and marital status.
- Respond to requests to describe experiences with and feelings about having bipolar disorder. (Participants are free to decline to answer any question or to decide to stop the interview at any time. The interviewer may decide to stop the interview if the participant seems to be experiencing distress.

**What are the risks of participating in this study and how will these risks be minimized?**

No harm is expected through participation in this study. Some people may feel sadness or anxiety while they describe their experiences with bipolar disorder. Participants may
choose to stop the interview at anytime. If distressing feelings arise participants may contact their own medical provider for assistance or Ingham County Community Mental Health Emergency Services at 517-372-8460 or the Listening Ear Crisis Center at 517-337-1717. Any participant or person who fails to qualify as a participant who does express current suicidal thoughts will be strongly encouraged to contact their provider or Ingham County Community Health Emergency Services. Richard Freedberg, the student investigator can assist with those contacts. As a licensed mental health professional (Registered Nurse), Freedberg will stop the interview if he feels that is needed. As a mandated reporter, Freedberg is obligated to inform authorities if he feels a participant is at risk to him or herself

What are the benefits of participating in this study?

There are no direct benefits to participants other than the satisfaction of sharing their story or contributing to the body of health care knowledge.

Are there any direct costs and is compensation associated with participating in this study?

There are no direct costs to participate. There may be indirect transportation and parking costs. Participants who complete the interview will receive a $25 gasoline card from a local service station in appreciation for their time and to help with any transportation and parking costs.

Who will have access to the information collected during this study?
The only people who will have access to the interview audio-recordings and notes are Richard Freedberg, the student investigator, and his advisor and dissertation committee members. The summarized information from all interviews and isolated quotes that cannot be identified with specific participants may be used in written reports or journal articles.

What if a person wants to stop participating in this study?

Participants can choose to stop at anytime for any reason without any prejudice, penalty, or negative consequence if they decide to stop participating. The investigator, Richard Freedberg, also may decide to stop the interview if he judges it to be in anyone’s best interests.

Who should you contact if you have questions?

Any questions prior to or during the study can be directed to the doctoral student investigator, Richard Freedberg by calling 517-599-4169 or by emailing him at richard.p.freedberg@wmich.edu. Questions can be directed to his faculty advisor, Dr. Nickola Nelson by calling 269-387-7990 or emailing nickola.nelson@wmich.edu. Participants also may contact the Chair of the Human Subjects Institutional Review Board at 269-387-8293 or the Vice President for Research at 269-387-8298 if questions arise during the course of the study. This consent document has been approved for use for one year by the Human Subjects Institutional Review Board (HSIRB) as indicated by the stamped date and signature of the board chair in the upper right corner. Do not participate if the stamped date is more than one year old.
I have read this informed consent document. The risks and benefits have been explained to me. I agree to take part in this study.

Please Print Your Name

Participant’s signature
Appendix C

Demographic Questionnaire
Demographic Questionnaire

1. What is your sex? Male _____ Female _____

2. What is your age? _____

3. Indicate what race or races you consider yourself to be (check all that apply):
   - Black or African American _____
   - White _____
   - American Indian or Alaskan Native _____
   - Asian _____
   - Native Hawaiian /Other Pacific Islander _____

4. Are you Hispanic/Latino? Yes _____ No _____

5. Do you have children? Yes _____ No _____ If so, how many _____

6. What is the highest degree or level of school you have completed?
   - a. Less than high school _____
   - b. High school diploma or GED _____
   - c. Some college _____
   - d. Associate’s Degree _____
   - e. Bachelor’s Degree _____
   - f. Master’s Degree _____
   - g. Doctoral or Professional Degree _____

7. What is your approximate family yearly income? __________

8. When were you diagnosed with bipolar disorder? __________

9. Have you been diagnosed with other medical or mental health conditions? ________________________________
   ________________________________
   ________________________________

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10. Do you take medication for bipolar disorder?
Appendix D

Open-ended Interview Instrument
Open-ended Interview instrument

Opening statement to be read to participant prior to starting interview: Please remember that I, Richard Freedberg, am the only person who will have access to the interview recordings or notes. The other three members of my dissertation committee (Dr. Nelson, Dr. Lagerwey, and Dr. Ross) also may see the transcripts. Only summarized information or isolated quotes without identifying data will be used in written reports or articles. You can choose to not answer any particular question or stop participating in this interview at any time for any reason. I can also decide to stop the interview if I feel that it is in anyone’s best interests to do so.

Questions and Potential Follow-up Probes

Introduction

1. Why were you interested in participating in this study? (Tell me more about that.)

2. How do you feel about participating?

3. How would you describe your mood and energy level right now? (Any recent changes in either? – tell me about that.)

Diagnosis history

4. How did you first learn that you had bipolar disorder? (Tell me more about the circumstances. How old were you at the time? What else was going on in your life then? What kinds of feelings or thinking did you experience?)
5. Can you describe your feelings when you first learned about it? (Tell me more about that.)

6. Have you been diagnosed with any other mental or physical health diagnosis?

7. Could you tell me a story from your experience that would help me and others understand what it is like to have bipolar disorder? (What are important things for the listener to learn from your story?)

8. What kinds of advantages or difficulties have you experienced in connection with your bipolar condition? (Tell me about the best times in your life? Tell me about the most difficult times in your life.)

Treatment

9. What medicines or other treatments have you used for your bipolar disorder? (What types of things have worked the best? Have you had any troubling side affects? What medications and other treatments do you use now? How is your current treatment working?)

10. Tell me about your relationships with your healthcare providers. (Tell me more about that.)

11. Is there anything that you would tell nurses or other professionals about helping people with bipolar disorder?

Family and friend relationships

12. Tell me about the family you grew up in. (How close would you say you are to your family? Describe how supportive they have been and are to you.)
13. Have you been in a committed relationship? Are you now? (Tell me about your past relationships.)

14. Have you started a family of your own? (What are you feeling? How do you think it is going? Tell me more about that.)

15. How would you describe your relationships with friends? Do you have a best friend or friends? (What do you think are the best things about that (those) friendship(s)?)

Employment

16. Tell me about your work history. (Are you working now? Doing what? How do you feel about your work?)

Coping, self-image

17. Can you tell me about what role, if any, spirituality or religion plays in your life? (Tell me more about that.)

18. What feelings do you have right now when you think about living with bipolar disorder? (Tell me more about that.)

19. When a person with bipolar disorder gets to feeling really down about himself/herself, what could he/she do to feel better? (What are some other possibilities? What has helped you the most, in what way?)

20. What are your feelings about the future?

21. Is there anything related to living with bipolar disorder that I should have asked but didn’t?
Appendix E

Stage Two Analysis Sample
Stage Two Analysis Sample

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Appendix F

Stage Three Analysis Sample
Stage Three Analysis Sample (taken from columns 2, 3 and 4 of stage two)

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Appendix G

HSIRB Approval Letter
Date: June 25, 2019

To: Nicholas Nelson, Principal Investigator
    Richard Breedberg, Student Investigator for dissertation

From: Amy Nangle, Ph.D., Chair

Re: HSIRB Project Number: U-04-08

This letter will serve as confirmation that your research project titled "Living with Bipolar Disorder" has been approved under the full category of review by the Human Subjects Institutional Review Board. The conditions and duration of this approval are specified in the Policies of Western Michigan University. You may now begin to implement the research as described in the application.

Please note that you may only conduct this research exactly as in the form it was approved. You must seek specific board approval for any changes in this project. You must also seek reapproval if the project extends beyond the termination date noted below. In addition, if there are any unanticipated adverse reactions or unanticipated events associated with the conduct of this research, you should immediately suspend the project and contact the Chair of the HSIRB for consultation.

The Board wishes you success in the pursuit of your research goals.

Approval Termination: April 27, 2011